

**DELIRIUM AND THE GOOD DEATH:
AN ETHNOGRAPHY OF HOSPICE CARE**

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Abstract

Delirium is a disturbance of consciousness and cognition that affects many terminally ill patients before death. It can manifest as confusion, hallucinations, and restlessness, all of which are known to be distressing to patients, families, and professional caregivers. Underlying the contemporary palliative care movement is a belief in the idea that a good death is possible; that dying can be made better for patients and families through the proper palliation of distressing symptoms and through proper attention to psychological, social, and spiritual issues that affect wellbeing at the end of life. Given that delirium is potentially disruptive to all that the good death assumes, i.e., mental awareness, patient-family communication, peace and comfort, the question was asked: What is the relationship between end-of-life delirium and the good death in hospice care? Ethnographic fieldwork was conducted at a freestanding residential hospice over a period of 15 months in a suburban community in eastern Canada. The research methods included participant observation (320 hours over 80 field visits), interviews with 28 hospice caregivers, and document analysis. The findings of this study provide an in-depth examination of the nature of caregiving relationships with patients and with families in end-of-life care. They illustrate how a commitment toward providing for the good death prevails within the cultural community of hospice, and how the conceptualization, assessment, and management of end-of-life delirium are organized within such a commitment. In this setting, experiences of conscious and cognitive change in dying are woven by hospice caregivers into a coherent system of meaning that is accommodated into prevailing scripts of what it means to die well. At the same time, delirium itself provides a facilitative context whereby processes of supporting families through the patient's death are enabled. This study highlights the relevance of considering the contextual and cultural features of individual end-of-life care settings that wish to examine, and perhaps improve, the ways in which care of delirious patients and their families is provided.

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Chapter 1: Introduction

Origin of an Idea

The idea for this project originated in January of 2008. At the time I was a first-year doctoral student, and I was invited by my research supervisor to participate in a meeting that brought together academics and clinicians with expertise in the respective fields of delirium and end-of-life care (EOLC). Delirium is a neuropsychiatric condition of acute onset and fluctuating course in which a person's level of consciousness (awareness of the environment) and cognition (thinking process) become disturbed (Fearing & Inouye, 2009). Delirium is an extremely common and distressing phenomenon in EOLC that is under-recognized by practicing clinicians and therefore presumably under-treated (Alici & Breitbart, 2009; Fang et al., 2008; Ski & O'Connell, 2006). The purpose of the meeting was to plan the adaptation of recently published clinical practice guidelines on the care of older adults with delirium (Canadian Coalition for Seniors Mental Health [CCSMH], 2006) to the EOLC context. This was felt necessary because while broad guidelines for delirium care are typically included in existing clinical practice guidelines for EOLC (e.g., National Comprehensive Cancer Network [NCCN], 2012) these lack sufficient depth in guiding clinicians' responses to the multiple and complex challenges that delirium causes in EOLC.

In our discussions over the course of this two-day meeting, which focused largely around the assessment and diagnosis as well as the pharmacological and non-pharmacological management of delirium in elderly dying patients, I was particularly intrigued by questions of how delirium affects the relationships between patients, families, and healthcare providers in EOLC. Certainly, it seemed clear from the available evidence that delirium posed significant relational challenges to the end-of-life experience. For example, we knew from research studies conducted with patients who remember their delirious episodes that these are severely distressing and can provoke a felt sense of alienation from others (Duppils & Wikblad, 2007). We also knew that family members have a strong need for communication with their dying loved ones and that because delirium threatens the potential for meaningful interaction, they are often ambivalent towards healthcare providers who employ pharmacological sedation as a treatment strategy (Brajtman 2003; Morita et al., 2007). As we attempted over the

course of this first meeting and our subsequent work together to draft care guidelines on the EOLC of terminally ill patients with delirium, relational challenges such as these stood out for me as crucially important. I was beginning to appreciate that it is one's relationships, with family, with care-providers, with something/someone transcendent, and/or with self, that ultimately shape and determine the plot of the end-of-life experience (Cairns, Thompson, & Wainwright, 2003; Gelfand et al., 2005; James, Andershed, & Ternestedt, 2007; Ingallinera, 2009). To me, this meant that within the end-of-life context, it is through attending to questions of human relationship that nursing finds its meaning and core purpose (Ferrell & Coyle, 2008; Wu & Volker, 2009). I therefore became interested in the potential for a research study that would focus analytic attention to the multitude ways in which patients, families, and care providers *engage with each other* in situations of delirium and EOLC.

Four months later, in April of 2008, I began work as a bedside nurse on the palliative care unit of a large hospital in Montreal. This unit is well recognized for the quality of EOLC that it provides. This was my first clinical job as a new nurse, and I revelled in it. I was in awe of the resilience and strength of human spirit that I witnessed in our patients and their families as they faced their own end-of-life situations, always in their own unique ways. I was inspired by the skilful and compassionate care that was delivered to patients and families by our team. I felt, and continue to feel, that end-of-life nursing provides tremendous opportunity for the enactment in practice of fundamental nursing values about which I am passionate and committed; values such as presence, comfort, quality of life, and dignity. At the same time, however, immersion into a landscape of suffering and death proved challenging. I remember admitting a young woman who, when I asked her about her goals, stated emphatically through her tears: "Give me chemotherapy, I want my life back. I want to live!" She died within a few days. Another man with terrible pain on movement angrily yelled: "Just kill me! Let me die!" as we turned and cleaned him. Experiences such as these instilled within me a growing disconnect between my faith in quality EOLC as truly able to help people to *live* until they die (e.g., Cramer, 2010) and the acknowledgement that for some, suffering persists despite the best in EOLC (Byock, 1994; Breaden et al., 2012).

Eager to further explore the conceptual underpinnings of end-of-life nursing in light of the challenges I was facing, I turned my attention toward the concept of the good death (e.g., Kehl, 2006; Kring, 2006; Ruland & Moore, 1998). This notion seemed to rest on specific attributes such as mental awareness, retaining control, being comfortable, achieving a sense of closure, and optimizing relationships in facing the end of life. Successfully providing for a good death was purported to result in specific desirable outcomes such as peaceful memories for the bereaved and professional satisfaction for healthcare providers. Having already been introduced to the difficulties that delirium poses to the end-of-life experience as described above, I was immediately preoccupied with the question of how a good death might be feasible when delirium becomes part of the clinical trajectory in dying. In juxtaposing the attributes of each, e.g., confusion/mental awareness, impaired communication/saying-goodbye, loss of control/being in control, delirium and the good death seemed irreconcilable. I wondered, in expert EOLC practice, how are these tensions navigated? Is the good death a relevant goal when patients become delirious, or does the idea of a good death with delirium imply a contradiction in terms?

Clarification of Terms

Terms such as *palliative care* and *hospice care* are used variably in the literature and public discourse, sometimes interchangeably and sometimes to mean different things (O'Connor, Davis, & Abernethy, 2010). Therefore, it is important to clarify how I will use these terms in this thesis.

Palliative care is a philosophy and a practice that focuses on the care of patients and families facing life-threatening illness (Registered Nurses Association of Ontario [RNAO], 2011). The essence of palliative care is about supporting such patients and families through interprofessional and whole-person care, to alleviate suffering and to promote quality of life in living as well as in dying. The overall goal is to foster experiences of wellbeing amongst people facing critical health situations through care, compassion, and clinical excellence (Corr, 2007; McIntosh & Zerwekh, 2006; Pastrana et al., 2008; Twycross, 2007). *Hospice* is one of several possible venues in which palliative care is delivered. For the purposes of this thesis, it refers to a freestanding residential care facility that provides palliative care to patients who are close to death.

Overview of Problem and Research Question

Dame Cicely Saunders, widely considered the founder of the palliative care movement, opened the first modern hospice, St-Christopher's, in London England in 1967. Saunders advocated an approach to care that would emphasize listening to the patient's own story of his or her illness, provide an environment to support relief, comfort, and accompaniment, and attend to the patient's total self: body, mind, family, and spirit (Saunders, 1965; Seymour, Clark, & Winslow, 2005). Her philosophy was a "middle way between too much and too little treatment" (Clark, 2007, p. 432). This meant neither subjecting inevitably dying patients to aggressive and futile medical interventions, nor abandoning them on the view that nothing more can be done. Five years before her death in 2005, Saunders (2000) published a reflection on the evolution of palliative care, affirming its basic principles. These include evidence informed symptom management, team based interprofessional care, patient-family as unit of care, support in bereavement, acknowledgement of and engagement with spiritual needs, and an overall commitment to "maximizing the potential the patient and family still have for activity, relationship, and reconciliation" (p. 11).

According to Hess (2003), illness can displace the sick into a foreign world of suffering and despair. Nurses help patients and families through this world. They provide a "safe harbour from which to manoeuvre through the vulnerability emanating from the illness experience" (p. 147). The palliative care model is similarly driven by the belief that it is possible and desirable to provide such a safe harbour for the dying and their loved ones. The good death provides an orienting framework from which this ethical commitment is enacted (Broom & Cavenagh, 2010; Clark & Seymour, 1999; Coward & Stajduhar, 2012). The good death is therefore a moral construct, i.e., it is something we *ought* to aspire to, that imagines experiences of wellbeing in dying. Palliative care attempts to foster good deaths through pain and symptom management as well as through psychological, social, and spiritual support of patient and family as inevitable death draws near.

Delirium is extremely common in dying patients. Prevalence rates vary between 20-40% in palliative care settings, with this incidence potentially climbing to 90% in the immediate time before death (Leonard et al., 2008). Thus, a significant minority if

not majority of terminally ill patients experience delirium before they die. While delirium is known to pose difficulties for the end-of-life experience of patients, families, and care providers, no study (to my knowledge) has examined the practice of palliative caregivers with explicit and concomitant focus to both delirium and good death. This is necessary, I believe, as current understandings of what it means to provide for a good death in palliative care are incomplete without accounting for the deteriorative cognitive changes that are so commonly characteristic of the dying experience in EOLC contexts.

The research question of this study is:

What is the relationship between end-of-life delirium and the good death in hospice care?

The objectives of this study are to:

- Articulate an emic perspective of hospice caregiving culture to interpret the practice of nurses and other caregivers in their facilitation of good deaths for terminally ill patients and their families.
- Articulate an understanding of how working toward the good death in hospice caregiving practice influences and is influenced by the conceptualization, assessment, and management of end-of-life delirium.

Outline of Chapters to Come

The second and third chapters of the thesis set the stage for this research. The literature review (Chapter 2) provides a conceptual overview of the topics of end-of-life delirium, palliative care, and the good death. Analysis of the literature reviewed reveals that delirium and the good death occur in a relational context. In Chapter 3, I describe the theoretical and methodological approaches underpinning this study. The relevance and appropriateness of an interpretive and constructivist approach are discussed. Where previous literature (Chapter 2) identifies the moral significance of delirium and the good death within a context of patient, family, and caregiver relationships, relational ethics is proposed as a guiding theoretical framework for this project. Chapter 3 also provides an overview of ethnography as the chosen methodological approach and a description of the specific methods used to generate data. Considerations of research ethics and research integrity (trustworthiness) are

also found in Chapter 3.

In this study, questions about end-of-life delirium were considered within the broader context of hospice caregiving culture. Therefore, presentation of the findings begins with a description and interpretation of the context of the hospice setting. I describe and interpret the daily practices, routines, and shared values of hospice caregivers (Chapter 4), and then examine the meaning of the good death within this cultural community (Chapter 5). These two chapters respond to the first research objective stated above about hospice caregiving culture. Presentation of the findings then progresses toward a more specific focus on end-of-life delirium, responding to the second research objective about its conceptualization (Chapter 6) as well as assessment and management (Chapter 7) in hospice caregiving practice. Read together, these four findings chapters offer an interpretation of the ways in which end-of-life delirium and the good death interrelate within the hospice context, i.e., how delirium affects the fostering of a good death, and also how conceptions of the good death influence the conceptualization and management of delirium.

Chapter 8 provides a general discussion of the study findings, drawing on previous studies of EOLC practice. The discussion is organized around five main themes that appear to characterize the study findings, and oscillates back and forth between broad interpretations of hospice caregiving culture (the fostering of good deaths) and focused interpretations of the ways that delirium care practices are manifest within this cultural context. An account of the research limitations, implications for nursing practice and education, and suggested directions for future research in this field are also presented in Chapter 8. The thesis concludes with a personal reflection as to the relationship between delirium and the good death in EOLC, and the impact this research has had on my own development as a palliative care nurse and educator.

Chapter 2: Literature Review

In this chapter, I draw on published literature from a variety of disciplines, chiefly nursing, medicine, and the social sciences, to provide a conceptual overview of the three most important topics relevant to this research study. These are 1) End-of-life Delirium, 2) Palliative Care, and 3) Good Death. Much of this literature was located by searching various databases, such as CINAHL, MEDLINE, PsycINFO, and Google Scholar, using a variety of search terms related to each of these three main concepts, e.g., “delirium” “confusion” “agitation” “restlessness” “palliative care” “terminal care” “hospice” “end-of-life” “end-of-life care” “good death” and “dying well”. I further broadened the scope of my search by retrieving cited and citing references for particular sources.

In this review, I first summarize the literature about end-of-life delirium as a clinical syndrome in the terminally ill. Within this literature I identify two discourses. A dominant discourse understands delirium as a medical event that is a clinical challenge to be overcome: it is a neuropsychiatric complication of dying. A less prominent though important discourse broadens this perspective and identifies delirium as a social phenomenon that has implications for the lived experiences of patients, families, and healthcare providers in end of life situations. From this reading, I propose that the conventional biomedical understanding of delirium as a neuropsychiatric complication of dying is important but incomplete, and that a more holistic understanding that brings into focus experience and relationship is necessary to better appreciate how delirium relates to giving and receiving care in end-of-life contexts.

Next, I review the literature about palliative care and good death, specifically through attention to two primary themes: dignity and relationship. Building on the work of others, I suggest that palliative care toward the good death can faithfully be described as a dignity-conserving practice that happens through relational engagement between caregiver and care recipient.

End-of-Life Delirium

Délire is nothing but a mental distraction, an error of the mind during wakefulness which causes it to judge badly of things known to all.

-DIDEROT et d'ALEMBERT, 1754 (trans. Berrios, 1999)

The term delirium comes from a Latin word meaning *to deviate from the furrow*, “to be crazy, deranged, out of one’s wits, to be silly, to dote, to rave” (Adamis et al., 2007). It is commonly used to refer to a state of wild excitement or madness (White & Bayer, 2007). Throughout history, delirium has been recognized as an indicator of worsening health and a harbinger of impending death (Shuster, 1998). As a medical condition, it signifies “a global disruption in brain homeostasis” upsetting integrative cognitive, behavioural, and emotional functioning (Cerejeira & Mukaetova-Ladinska, 2011, p. 3). The clinical definition of delirium depends on specific criteria set forth by the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association [APA], 2000). These criteria identify delirium as a syndrome of disturbed consciousness (reduced ability to focus, sustain, or shift attention), together with changes in cognition or perception, with short onset and fluctuating course, and caused by a general medical condition (Bush & Bruera, 2009; CCSMH, 2006). The clinical presentation of delirium can seem similar to dementia, where with either condition patients exhibit global cognitive dysfunction (Lipowski, 1982) and “widespread failure of higher cerebral functions” (Caraceni & Bosisio, 2004, p. 233). Inouye (1994) laments the common misidentification of delirious elderly patients as demented in hospital settings. The critical distinction is that while dementia is characterized by cognitive deterioration that is chronic, progressive and irreversible, delirium is an acute and reversible confusional state (Caraceni & Grassi, 2011; Inouye, 2006). The sudden cognitive changes characteristic of delirium include problems with orientation, memory, language, and thought, while perceptual changes may be unrelated to cognitive performance and can include hallucinations and/or illusions (misinterpretations of real sensory stimuli) (Cerejeira & Mukaetova-Ladinska, 2011). Macleod (2006a) states that alterations in consciousness are the essence of delirium, where consciousness is the fusion of awareness, alertness, awakeness, arousal, attention, and vigilance; consciousness is how we know ourselves and our relationship

with our environment.

In the forthcoming version of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V), a change in the diagnostic criteria for delirium is planned. The current version (DSM-IV-text revised) identifies the first of four diagnostic criteria for delirium as: “A disturbance of consciousness, (i.e., reduced clarity of awareness of the environment) with reduced ability to focus, sustain, or shift attention.” It is anticipated that this first criterion will be rewritten to identify delirium as: “A disturbance in attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and orientation to the environment.” The rationale for substituting “consciousness” with “attention and orientation” is that consciousness is now thought to be too nebulous a term to guide diagnostic assessment. The proposed revision suggests that attention and orientation more effectively describe a patient’s state of *awareness*, which remains the most important concept in conveying the essence of delirium (APA, 2012).

As mentioned in Chapter 1, prevalence rates for delirium vary between 20-40% in palliative care settings, but this rate climbs as death approaches. Incidence of terminal delirium (i.e., delirium in the days or hours before death) is as high as 85-90% (LeGrand, 2012; Leonard et al., 2008). Leonard et al. (2008) explain that the wide variety in reported prevalence is due to differences across studies in how delirium is defined and measured. What is clear, however, is that delirium is common in patients at the end of life, particularly in the time just before death (Breitbart & Cohen, 2000; Breitbart & Strout, 2000; Cassarett & Inouye, 2001; Centeno, Sanz, & Bruera, 2004; Lawlor et al., 2000).

Delirious patients manifest a wide variety of psychiatric and psychological symptoms (Macleod, 2011), including anxiety, delusions, mood lability, alterations in sleep-wake cycles, and motor disturbances (Cerejeira & Mukaetova-Ladinska, 2011; Stagno, Gibson, & Breitbart, 2004). Delirious patients present with one of three subtypes: hyperactive, hypoactive, or mixed (CCSMH, 2006). Hyper-active delirium manifests as a state of elevated arousal and is characterized by restlessness and agitation (Breitbart & Alici, 2008). Agitated delirium results in a chaotic scene in which the patient’s thought disturbances convey fear, anxiety, and mistrust. This results in a shared sense of distress amongst patients, families, and professional care providers

(O'Malley et al., 2008). End of life agitation has been called “the single most painful expression of the dying experience” (Maluso-Bolton, 2000, p. 9), and is considered a palliative care emergency (Roth & Breitbart, 1996). Patients with hypoactive delirium, meanwhile, are lethargic, and mixed delirium refers to a fluctuation between the two presentations. Clinicians often overlook hypoactive delirium (Inouye, 1994). It is a particular problem for EOLC when patients who appear withdrawn are mistakenly labeled as fatigued, depressed, or as following a predictable pattern of decreased alertness in dying (Marchington, Carrier, & Lawlor, 2012; Leonard et al., 2009; Spiller & Keen, 2006). While patients with hyperactive delirium are more likely than non-delirious patients to suffer injuries as a result of falls, patients with hypoactive delirium are more likely to suffer consequences of immobility such as pressure ulcers and infection (LeGrand, 2012). When patients who recover from delirium are asked about their experiences, the level of distress caused by hypoactive and hyperactive forms are similar (Breitbart et al., 2002; Bruera et al., 2009). All patients with delirium in the EOLC setting (hyper or hypoactive) are less able to participate in decisions affecting their care, less able to benefit from psychosocially supportive interventions (e.g., counseling), less able to communicate with their families in meaningful ways, and less likely to receive optimal pain and symptom management (Lawlor & Bruera, 2002).

The physiological causes of delirium in terminally ill patients are invariably complex and multi-factorial (LeGrand, 2012; Morita et al., 2001). Cases of delirium at the end-of-life are potentially attributable to medications administered (e.g., opioids, steroids, benzodiazepines, anticholinergics), drug or alcohol withdrawal, and/or to features related to the underlying illness process (e.g., dehydration, hypoxia, infection, brain metastases, metabolic disturbances, organ failure). The pathophysiological mechanisms of delirium are not fully understood, but it is thought to result from changes in neurotransmitter activity levels in various locations of the brain (LeGrand, 2012). A current theory is that delirium is chiefly a problem of acetylcholine, where decreases in cholinergic activity and corresponding disruptions in dopaminergic, adrenergic, and serotonergic activity account for the symptoms observed (Hsieh et al., 2008).

In the conventional paradigm of medical care, the clinical objective is to cure

delirium through identification and treatment of underlying etiological factors (Meagher, 2001; White & Bayer, 2007). At the end of life, however, reversal of delirium is often not feasible. This is either because it is caused by advanced and irreversible illness processes or because goals of care at this stage do not accommodate the invasive investigations and/or treatments that attempts at reversal require (Casarett & Inouye, 2001; Kress & Hall, 2004; Leonard et al., 2008; Lyness, 2004). The challenge for EOLC providers, then, is to manage delirious symptoms, often through pharmacological sedation. The goal is to promote comfort, restore a sense of peacefulness, and minimize the adverse implications of irreversible delirium on the overall quality of the end-of-life experience. Determining the (ir)reversibility of delirium at the end of life, however, is not straightforward. Deciphering terminal delirium, i.e., a terminal event occurring in the one to two days preceding death, from a delirium that is not a direct feature of imminent dying and therefore potentially correctable can only be established with certainty *after* the death of the patient (Brajtman et al., 2011). Up to half of cases in end-of-life contexts may indeed be reversible (Lawlor et al., 2000). Premature identification of delirium as irreversible in EOLC may thus result in a “therapeutic nihilism” that misses opportunities to adequately respond to treatable cases (Lawlor & Bruera, 2002, p. 705). At the same time, a zealous approach to delirium reversal in terminal care may be futile and result in added burdens that cause more harm than benefit and that detract from focusing on the optimal palliation of the dying patient.

Delirium as a problem to be managed.

Dying is difficult, dying crazy is more difficult. Such ‘bad’ deaths may be preventable.

-Macleod, 2011, p. 135

Within the medical and nursing literature, a dominant discourse is evident that characterizes end-of-life delirium and its related manifestations as symptoms, syndromes, and conditions to be controlled and overcome. According to Boyle (2006), delirium is a “well-recognized barrier to quality of life” and “an important problem that requires sound nursing assessment and proficient intervention” (p. 62). Likewise, Breitbart and Alici (2008) speak of delirium as the “final challenge of palliative care management...[it is] the most common neuropsychiatric disorder that terminally ill patients face” (p. 2899). These authors are explicit in outlining specific outcome

criteria, which they see as indicative of optimal care:

In the last days of life, the ideal goal of delirium management is a patient who is comfortable, not in pain, awake, alert, calm, cognitively intact, able to communicate coherently with family and staff...When delirium is a consequence of the dying process, the goal of care may shift to providing comfort through the judicious use of sedatives, even at the expense of alertness. (p. 2903)

In this way, delirium management involves the calculated enactment of strategies to enable a peaceful death; to satisfy the normative standard set forth by Saunders and Baines (1983) that “with competent care almost all patients will sink quietly into unconsciousness and die peacefully” (p. 58-59). This standard of quietly slipping away and peacefully dying while asleep is reflected in more recent research conducted with patients, families, and care providers about what it means to experience a good death (De Jong and Clarke, 2009).

Guidance on clinical delirium care has been systematized by Macleod (2006b) in listing strategies that he refers to as the “cardinal rules” (p. 23) of managing delirium. These include 1) prevention, 2) treatment of the underlying cause, 3) creation of a safe environment, and 4) psychological and pharmacological intervention. A similar step-wise and algorithmic approach to management is consistently represented across different evidence-based formulations of delirium care, both for general care settings (e.g., Trzepacz et al., 1999) and for end-of-life contexts (e.g., Brajtman et al., 2011; NCCN, 2012). Medical care practices in responding to the delirious patient at end of life can include the rotation of opioids and cessation of other potentially delirium-causing medications, artificial hydration, calcium correction, and pharmacotherapy with antipsychotics, together with benzodiazepines only if the patient requires sedation (Breitbart & Alici, 2012; Bush & Bruera, 2009; Caraceni & Grassi, 2011)

There is a lack of research evidence into the nursing management of delirium in palliative settings, where guidance in this area is informed by expert opinions, single case reports, and review papers (e.g., Blanchette, 2005; Boyle, 2006; Brown & Degner, 2001; Lee & Washington, 2008; Maluso-Bolton, 2000). This literature reveals the nursing role in end-of-life delirium care as assessing for delirium using appropriate screening methods, striving to provide a safe environment, administering pharmacological treatments, searching for and correcting underlying causes where

feasible, offering informational and emotional support to family members, and implementing non-pharmacological interventions for patients. Non-pharmacological interventions include balancing sensory deprivation and sensory overload, avoiding ambiguous lighting, facilitating orientation through sensory aids and visual cues (e.g., eyeglasses, hearing aids, clocks, calendars) and communicating with the delirious patient in simple and reassuring ways (Moyer, 2011).

Dahlke and Phinney (2008) interviewed nurses working on medical and surgical units about their care of elderly patients at risk for delirium. These authors found that nurses described having limited time to care for such patients. Nurses spoke about their clinical management practices as attempting to control the situation, usually through some form of patient restraint. A survey of 867 nurses from 67 hospices across the United States conducted by Johnson et al. (2005) found that agitation and confusion were amongst the “most difficult to manage” (p. 73) of 32 different symptoms in EOLC. Interestingly, the predominant barriers identified by these nurses in managing agitation had to do with the patient and family either not wanting or being unable to implement or maintain the necessary treatments. This suggests that family and care provider conceptions of how end-of-life delirium should be managed might differ in important ways. Conversely, barriers identified in managing confusion were that this symptom is a “tradeoff” (p. 75), i.e., a consequence of other treatments, and that other more distressing symptoms limit the ability to treat this symptom. Dahlke and Phinney point out that, “if a child becomes confused, it would be recognized as an emergency requiring immediate attention, whereas confusion in older adults may be accepted as a natural occurrence.” (p. 46) Other authors similarly suggest that nurses’ approach to confused patients will depend on their own personal philosophies about what is ‘normal’ in aging and dying (Agar et al., 2012; McCarthy, 2003).

Sedation.

In a focus group study with palliative clinicians about their experiences of providing end-of-life delirium care, Brajtman (2005b) shows how care providers struggled to reclaim power that had been taken away by delirium. She writes that “use of medication allowed the team a critical measure of control over the patient’s behavior and perceived suffering, and increased their confidence in their ability to handle the

situation” (p. 173). When family members expressed ambivalence about the use of sedating medications, care providers would perform *experiments*, a manipulation of the clinical situation, as a way to fuse the family’s perception of patient suffering with their own. This is demonstrated in the following two quotes by a nurse and physician participant, respectively:

Sometimes families ask for a break from the sedation, we do it, but the restlessness returns and then they say ‘we are convinced, let’s go back to the sedation’” (p. 173; Nurse)

After this experiment [manipulating sedation] we do because of the mixed feelings, it usually finishes off the problem because it is so terrible for them to see the suffering again. By manipulating the sedation, it helps the family to understand that there is often no choice in this situation” (p. 174; Physician)

These examples point to the ethical complexity of responding to delirium in palliative EOLC, particularly around practices of palliative sedation. Palliative sedation is the therapeutic reduction or elimination of consciousness, either intermittently or continuously, when there is “no other way to gain control over one or more refractory symptoms” (Claessens et al., 2007, p. 102). Delirious agitation is one of the most common antecedents to palliative sedation in EOLC (Caraceni et al., 2012; Engstrom et al., 2007).

Woods (2004) argues that palliative sedation is an ethical care option within the spectrum of interventions used to alleviate suffering in dying. He suggests that some experiences are simply not worth having by virtue of their unpleasantness. He writes that:

...one’s capacity for living a good life depends on the quality of one’s experiences. Life is bad if every waking moment is overshadowed by an acutely unpleasant experience. Such a belief regarding the nature of a good life influences views on the nature of a ‘good death’. It follows that a good death is one in which unpleasant experiences are eradicated or minimized. (p. 244-245)

Despite the apparent consensus, within palliative care circles, that palliative sedation is an ethically viable option to respond to intolerable suffering, tensions remain. First, medications given to achieve sedation can themselves contribute to worsening delirium, which is problematic if continuous and deep sedation (until death) is not the desired goal (Caraceni & Simonetti, 2009). These authors further caution that

palliative sedation for “refractory” delirium should not substitute exhaustive efforts to treat and reverse the delirium whenever possible (p. 170). Sadler (2012) argues that the ways in which we understand *refractory* suffering in the end-of-life context are ambiguous, and that the conceptual divisions between palliative sedation, assisted suicide, and euthanasia are not as clear as we might like to believe. She calls for a reflective analysis of how we interpret the suffering of others, cognizant of the role that our own distress plays in our practice:

...at the bedside of the dying, nurses often find themselves confronting their own vulnerability concerning illness, suffering and death. They can protect themselves by distancing themselves from their patients. They are not always aware that their own sources of distress can become obstacles to address the suffering of others. Nurses must regularly consider the impact that the strong emotions such as fear and helplessness they feel at the sight of a suffering patient may have on the decision to initiate or participate in palliative sedation. The decision is most likely based on a desire to calm a suffering patient, but couldn't there also be more or less conscious motivations to want to calm themselves, as caregivers confronted with pains that defy them? (p. XX)

In her ethnographic study of EOLC, Lawton (2000) shows that the practice of sedation for terminal agitation is not only grounded by an ethics of beneficence, but is also performed to reinforce an ideological good death that requires “the location of ‘docile bodies’ within communal spaces” (p. 121). Further, Macleod (2009) warns that current practices of palliative sedation for delirium may be depriving patients of the opportunity to ‘lighten up’ before death. Lightening up involves a spontaneous return to pre-morbid conscious and cognitive states (i.e., a clearing of the mind) for a very brief period (a few hours) before rapid decline and death. While virtually no research has been conducted about this phenomenon, it is well known to caregivers of the dying. Macleod notes that, while rare, lightening up before death can be a tremendous gift for patient and family. He worries that the potential for its occurrence is being suppressed and therefore erased from contemporary deathbed scenes through practices of sedation in delirium.

An alternative discourse: delirium as a relational experience.

Conceptualization of end of life delirium as a problem to be managed dominates the current medical discourse (e.g., Breitbart & Alici, 2008, Caraceni & Simonetti, 2009;

Gagnon, 2008; Lawlor et al., 2000). Delirium is the “most common and often serious neuropsychiatric complication seen in patients with cancer” (Breitbart & Alici, 2012, p. 1206). Consideration of delirium as an exclusively medical phenomenon is, however, at odds with how some professionals working with terminally ill patients understand their experience.

A survey of palliative care professionals (n=130) representing medicine, nursing, social work, and pastoral care from three American hospice programs asked open ended questions about the definition, frequency, and associated behaviours of terminal agitation (Head & Faul, 2005). This study found that while physicians were more likely than other professionals to identify medical causes, participants overall inferred a greater number of perceived causes that were spiritual and/or psychosocial in origin. These included fear of dying, uncertainty regarding an afterlife, not being ready to die, unfinished business, emotional issues, family issues, and not being at peace.

Callanan and Kelley (1992) articulated an alternative perspective for understanding the behaviours of dying people that are typically labeled as confusion, hallucination, or disorientation. Their work is a compilation of 60 real life clinical cases showing that behaviours initially interpreted as confused ramblings, incoherent speech, or general agitation can be deciphered as deliberate attempts by the patient to communicate his or her experience of dying, or to request something that is needed for a peaceful death. While Callanan and Kelley do not deny the relevance of organic delirium, they suggest that in all cases the talk of the delirious patient, however confusing, might hold personal significance. Therefore an understanding that transcends a purely biomedical perspective is necessary. In a more recent book written for patients, families, and clinicians living and working within the realm of EOLC, Callanan (2008) criticizes the labels that both professionals and families apply to the supposedly nonsensical behaviours of dying patients. She writes that:

All of these caregivers are missing something vitally important. They are so busy labeling the person and dismissing his or her seemingly incoherent attempts to communicate as “crazy talk” or gibberish that no one is actually listening to the words and watching the behavior of the dying person. (p. 223)

The broadened conceptualization of end-of-life delirium that is called for based on these descriptions is analogous in many respects to the notion of *total pain* that is a key element of palliative care wisdom (Clark, 1999; Saunders, 1988). This concept requires that a person's pain experience be analyzed and understood through physiological, psychological, social and spiritual lenses to more accurately grasp the nature of the relationship that exists between pain and suffering (Mehta & Chan, 2008). The idea of total pain within palliative care "both reflects and reinforces a relational, intersubjective notion of the person/self" (Lawton, 2000, p. 159). It is meant to alert caregivers of the dying that suffering at the end-of-life goes beyond *and* is underpinned by the "physical agonies of the dying experience" (Kellehear, 2009, p. 390). Recently, the total pain model has been applied to other clinical phenomena of the dying process. For example, Abernethy and Wheeler (2008) propose that the total pain model can be translated to dyspnea (breathlessness) to more fully understand the physical, psychological, social, and spiritual implications of this symptom experience.

Although a thoroughly holistic ('total') conceptualization of delirium has yet to emerge, there is a current undertone within the delirium literature that calls for a broadened discourse that will expand our understanding beyond the biomedical and towards the personal and relational (Neville, 2006, 2008). A review by Belanger and Ducharme (2011) found only seventeen research articles that illuminate the subjective nature of the delirium experience from either the patient or nurse caregiver perspective, pulled from amidst a voluminous literature that over the past two decades has collectively "focused above all on the characteristics, pathophysiology, incidence, aetiology, and prognosis of delirium as well as on the prevention, detection, evaluation and management" (p. 304). Their review of these seventeen articles describes that delirium is an uncomfortable experience in which patients feel anxious, isolated, scared, and frustrated. Patients in a delirious state of mind seek to protect themselves by hiding their confusion, and flee from or fight off what they perceive to be a personal threat. Nurses, meanwhile, have difficulty trusting their delirious patients, who "became strangers who seemed to be in a separate world and whose reactions were unpredictable" (p. 311). In delirium, relationships between nurses and their patients

are therefore threatened. Nurses approach their patients with a desire to be present and helpful yet also feel a need to “keep their guard up” (p. 311) given the context of mistrust that delirium creates.

The mental state of the dying patient is an important determinant of how bereaved family members structure their memories of the dying experience. In a study of bereaved family members, Valentine (2008) found that mental clarity ensured that personhood was not lost despite a dying body. Continued mental capacity allowed for relationships to grow and to become more intimate as death approached. Mental absence and relational unavailability, however, was distressing and disorienting to loved ones. As one participant remembered,

...she wasn't really there...there'd be moments when she'd look at you and you'd suddenly see the look of recognition and then it would just be gone...she'd be back in this just hellish place where she was literally screaming...and we couldn't, you know, comfort her at all – and it was just way too painful to watch what was going on.” (p. 67)

Research into the subjective experience of delirium from the perspectives of patients whose delirium resolves reveals that during delirium patients live a paradoxical reality of contradictions (e.g., real-unreal, awake-dreaming, present-past) and live through scenes that are dramatic and provoke strong emotions such as anger, fear, panic, insecurity, and sometimes delight (Duppils & Wikblad, 2007). Findings from a phenomenological study of elderly patients who recovered from delirium speak to the impact of delirium on family relationships:

One man noted, “I was confused to the point that I told my wife, ‘I’m angry at you, I’m angry at my children,’ because nobody came to my rescue.” Another angrily blamed his daughter for his being restrained, “It’s your fault that they got me tied down...because you are the one who had them to do it.” (McCurran & Cronin, 2003, p. 321)

The subjective experience of delirium at the end-of-life has been the focus of both quantitative and qualitative investigation. Breitbart et al. (2002) conducted a prospective, systematic evaluation of delirium recall and related distress in a sample of 101 patient/family/nurse triads. Of this sample, severe distress was reported by eighty percent of patients, seventy-six percent of family members, and seventy-three percent of nurses. More recent quantitative research of recall in patients having been delirious

further supports our understanding that delirium is lived as a distressing experience (Grover & Shaw, 2011). For example Bruera et al (2009) found that in a sample of 99 advanced cancer patients with a resolved delirium, 74 percent of these recalled the experience, and many were distressed by memories of delusional thoughts, psychomotor agitation, and disorientation to time and space. Buss et al. (2007) found that in a sample of 200 family caregivers, those who perceive patients to be confused and delirious are at increased risk for generalized anxiety. In this study the witnessing of delirium was more strongly associated with family member anxiety than other symptoms such as vomiting or insomnia, or than feeling that the patient has “had enough” (p. 1088).

In a descriptive phenomenological study with close relatives of older hospitalized adults with delirium, Stenwall et al. (2008) identify the family experience as suddenly encountering unfamiliarity in a familiar person. Family members in this study considered the patient as inhabiting an alternative reality, and tried to reach this new reality. The study authors interpret these family members’ experiences as feeling “insecurity, sadness, vulnerability and distress ... loss of a loved and familiar person, who they do not know if they will meet again” (p. 246).

Qualitative interview studies by Brajtman (2003; 2005a; 2005b) and Brajtman, Higuchi, and McPherson (2006) have investigated the experience of delirium in palliative care contexts from the perspectives of family members and healthcare providers. This research has shown that the experience of suffering in terminal delirium spans physical, emotional, and spiritual dimensions. Findings reveal a diversity of family beliefs concerning the behavioural manifestations of EOLD. For example, some families interpreted agitated behaviour as though their loved ones were scared to die and were “expressing their feelings toward the enemy [death] who was advancing relentlessly toward them” (Brajtman 2005a, p. 76). Other family members believed that patient restlessness was instead a bodily expression of anger, frustration, or feeling out of control. The interesting common thread to these beliefs is the attribution of agency to the delirious person and an inferred sense of purpose that underlies the behavioural manifestations witnessed. Additionally, family members spoke of a desire to communicate with their dying loved ones (e.g., needing to say

good-bye) and were ambivalent about delirium treatment strategies such as pharmacological sedation. Professional caregivers, for their part, were emotionally affected by the suffering they witnessed and reported that observed experiences of delirium were incompatible with their own expectations of a peaceful death for their patients. Also, while they engaged in deliberate efforts to alleviate the suffering they encountered, they too sometimes felt ambivalent about treatment options that they feared might hasten death or deprive patients of functioning and vitality.

Namba et al. (2007) lend further credence to the psychosocial-spiritual complexity of the delirium experience. They conducted interviews with bereaved family members of cancer patients who had delirium in the two weeks prior to death. Participants stressed that incoherent speech that was perceived as strange to healthcare providers often held meaningful significance in the context of the patient and family's personal life story. Participants therefore expressed a desire for healthcare providers to respect the subjective world of patients during delirious episodes and to actively inquire about what a patient's delirious behaviour might mean, instead of adopting a dismissive or reality-orientation approach. Here again, respecting the delirious person's agency and recognizing an underlying meaning to his or her communication seems to be important. It would appear however that care still needs to be improved in this area. Morita et al. (2007) found in a cross sectional survey of 242 bereaved family members that the majority felt distressed or very distressed about the experience of terminal delirium, close to a third reported a need for improvement in the care that they received, and over half had ambivalent feelings about management strategies employed.

Based on the literature reviewed above, it is evident that delirium poses unique relational challenges for patients, families, and care providers in end-of-life situations. Therefore, the conventional medicalized understanding of delirium as a neuropsychiatric complication of dying is incomplete without a complementary understanding that focuses experience and relationship and that strives to appreciate how delirium relates to giving and receiving care in end-of-life contexts.

Palliative Care

Patients and families have much at stake in end-of-life situations. Dying is one of life's greatest challenges, the experience of which can span the entire spectrum of human emotion from severe distress to profound wellness (Byock, 1996). Nurses' actions and interactions with patients and families can influence the meanings they attribute to their experiences of serious illness (Larkin, 2010; Meiers & Brauer, 2008; Mok & Chiu, 2004). There is great potential for health promotion, and there is great potential for harm. When patients and families do not feel supported and cared for, the stage is set for feelings of hopelessness, anger, and betrayal, as conveyed in the following passage by a dying man's daughter:

How can I explain to you how I experienced your presence as you cared for my dying father? We were trapped; trapped in a system, mechanized, sanitized, dehumanized; all rubber gloves, measurements and cold assessing stares. You proudly wear, you *hide* behind the carefully crafted labels pasted on your foreheads. "Objectivity," "Professionalism," "Competence." Your world is surrealistic. Stop time, I cannot hear you. You do not seem to know or care that my world is whirling apart. My view of self, of them, of HIM is disintegrating. He is dying. Dying! My world screams in disbelief. This is impossible! He is crumbling and so are we. (Mount, 1993, p. 29, original emphasis)

The development and growth over the later half of the twentieth century of the palliative model of care was in response to dissatisfaction with how modern medical culture attends to death and dying (Clark, 2002; Field & James, 1993). According to Smith (2000), a "soulless death in intensive care is the most modern of deaths" (p. 129). Palliative care is itself a "symbolic critique of how dying people are managed in highly medicalised settings" (McNamara, 2004, p. 930) and is put forward as "an alternative to inappropriate cure-oriented care for the dying" (Northcott & Wilson, 2001, p. 68).

Several important and influential studies have illuminated what Canadians are most concerned about as they face the end of their own lives. A large scale, qualitative interview study conducted at sites in Toronto with one hundred twenty-six participants (living on dialysis, with human immunodeficiency virus (HIV), or in long-term care) revealed that major domains of quality EOLC from patients' own perspectives are pain and symptom management, avoiding a period of prolonged

dying, achieving a sense of control, relieving burden on others, and strengthening relationships with significant others (Singer, Martin, & Kelner, 1999). Participants in this study who spoke of not wanting their dying prolonged used words such as “suffer,” “dignity,” and “peace” in their narrations, e.g., “I didn’t want to be kept alive artificially forever just to die later on and suffer” (p. 165). Subsequently, Heyland et al. (2006) surveyed seriously ill hospitalized patients across five Canadian sites (with advanced cancer, chronic obstructive pulmonary disease, congestive heart failure, or liver cirrhosis) about the perceived importance of various elements of quality EOLC. These elements were pre-determined by the study authors based on a synthesis of published literature on quality EOLC as well as a pilot interview study with seriously ill hospitalized patients. Of a sample of four hundred and thirty-four patients, greater than ninety percent rated as either very or extremely important elements related to: having trust and confidence in the doctor and nurses involved in their care, receiving honest and understandable illness information, not being a burden on family, having good symptom relief, and receiving healthcare that is respectful and compassionate.

We have known now for many years that dying patients experience multiple difficulties that cause or compound suffering, and that the general health system is not adequately responsive to their needs (SUPPORT Principal Investigators, 1995; Teno et al., 2004). Despite the advent of palliative care and current calls to integrate palliative principles into mainstream approaches (Meghani 2004), the aggressiveness (cure oriented focus) of medical care delivered at the end of life (e.g., chemotherapy, emergency room visits, intensive care unit admissions) may be increasing (Earle et al., 2008). A Canadian study by Hui et al. (2009) analyzed the care given to all patients who died at the Vancouver Cancer Center over a two year period (n=118). Ninety-one percent of these patients had tests performed during their last week of life, and twenty-eight percent had tests performed on their last day of life. Thirty-eight percent of patients received either chemotherapy or radiation therapy within the last two weeks of life despite poor functional status that likely contraindicated such treatment. One patient with a do-not-resuscitate order in place “mistakenly” received cardiopulmonary resuscitation (p. 877). According to Wentlandt and Zimmermann (2012) “care at the end of life continues to be aggressive, counter to established quality

indicators and practice guidelines for end-of-life care” (p. 81). A recent analysis of the evolution of palliative care in Canada (Williams et al., 2010) finds that palliative care currently resides at the margins of a healthcare culture that is death-denying, curative and bio-medical in focus, and “more interested in healing the bio-physical body rather than attending to the psycho-social and spiritual elements of the dying being” (p. 4).

There is growing recognition that tailoring our care of terminally ill patients and families according to their own values, preferences, and priorities is a moral imperative. Davies and Higginson (2004) suggest that people who are dying are among the most vulnerable in our society, and that the quality of care that they receive is a reflection (or indictment) of our collective humanity. Quality care at the end of life is not simply about offering and respecting patient choice. Decision-making happens through relationship, and people require support in making choices when confronted with the possibility of their own death or the death of a loved one (Cassell, 2007; Murray et al., 2004). Quality EOLC, then, means genuine engagement with patients and families as they clarify and prioritize their values and their wishes within the ever evolving context of their given circumstance. In this way, health care providers support patients and families to articulate and achieve whatever goals they might have for their own end-of-life experiences (Wright & Pugnoire-Gros, 2012).

Good death.

Few trust nature to produce a good death

-Northcott & Wilson, 2001, p. 67

In their review of dying and death in the context of Canadian institutions, the authors of the above quote are referring to the common inclination by hospital care providers in end-of-life situations to medically treat the manifestations of dying, e.g., infection, desaturation, hypovolemia and dehydration, without acknowledging unavoidable and imminent death. In such situations, vision of the whole is lost through the medical micromanagement of physiological changes intrinsic to the natural dying process (Fins, 2006). When death does eventually happen in these situations, it is experienced as a failure, and families feel confusion and shock at how ‘suddenly’ the patient died. Levetown (2006) laments such surprise deaths within acute medical care, stating that while death itself is inevitable, “missed goodbyes are not” (p. 930).

According to McNamara and Rosenwax (2007), dying today is “dreadfully mismanaged” (p. 373): “painful, undignified, and medicalised” (p. 375). These authors argue that dying people and their families have to fend for themselves in facing their end-of-life situations, as the structures we have established provide little in the way of helpful support. The palliative care movement proposes a direct alternative to the “disgraceful” (p. 375) ways in which many Westerners die. This movement seeks to reclaim dying from the clutches of mainstream biomedicine and re-conceptualize it as a normal human process. By acknowledging the normalcy of eventual death in the context of inevitably life-limiting illness, proponents of a palliative ethic eschew undue medicalization to create time and space to focus on other (purportedly more important) needs of dying patients and their families. These are thought to include, among others, the need to be free of physical pain, the need to express feelings and emotions in personal ways, the need to be cared for with compassion, the need to seek spirituality, and the need to die in peace and dignity (Kessler, 2007). These needs appear compatible with other themes identified by Steinhauser et al. (2000) in an influential large-scale interview and focus group study that explored the idea of a good death from the perspectives of patients, families, and health care providers. In seeking to understand what people value as they face end-of-life situations, these authors identified that being comfortable (symptom management), participating in decision-making, being prepared for death, being cared for as a whole-person, and being able to contribute to others (reciprocity) are important elements of the good death.

Consistent with an ethos that acknowledges the normalcy of human death, the idea of *allowing natural death* is often invoked to advocate for the abstention from seemingly unnecessary and unhelpful medical interventions that cause suffering and detract from the potential to achieve positive outcomes in end-of-life situations (Zimmermann & Wennberg, 2006). Interestingly however, death as managed within a palliative care framework is, arguably, no more natural than other medical alternatives. While palliative care practices might not intervene at the level of illness progression, insofar as palliative care “intends neither to hasten or postpone death” (Canadian Hospice Palliative Care Association [CHPCA] nursing standards committee, 2009, p. 9), they nonetheless are interventionist activities. Palliative caregivers intercede in the

natural dying of others to provide symptom management as well as psychological, social, and spiritual support. Specifically, the vision of the palliative care movement is to provide “care that aims to relieve suffering and improve quality of life throughout the illness and bereavement experience, so that patients and families can realize their full potential to live even when they are dying” (Ferris et al., 2002, p. v). Thus, death within palliative care is a *managed* death.

Sandman (2005) notes that while the idea of natural death enjoys widespread popularity within the field of palliative care, it is unhelpful and misleading for understanding what is at stake in end of life situations and for guiding action in caregiving. He juxtaposes natural death with unnatural death as the former being caused internally, i.e., death resulting from illness, and the latter being caused externally, i.e., death resulting from an accident, suicide, or being killed by another. With this juxtaposition the question of whether to intervene medically to prolong someone’s life and dying in the context of life limiting illness is really a question of “facing a choice between an internally caused death now or an internally caused death later, in other words, between a natural death now or later” (p. 276). He further notes that prolonging someone’s life through medical intervention cannot be said to rob them of a natural death, as most palliative care patients have already had their lives prolonged in earlier contexts of curative therapy. More relevant considerations, he suggests, are how interventions offered at the end-of-life actually affect the individual circumstances of someone’s dying and death. Personalized and individual conceptions of quality of life, dignity, or peacefulness may play a role in this analysis; ultimately the question is about what *value* do we provide to people through the care we deliver at the end of life?

Emanuel and Emanuel (1998) suggest that a good death is a clinical outcome, it is something that can be provided for through appropriate care. They appeal to covenantal notions of care provider - recipient relationships by labelling the good death as a *promise to be fulfilled*, and argue that good death should become the standard of care in clinical work with the terminally ill. For them, the good death involves an experience of meaning and value during the last weeks of life and is achieved depending on complex interrelationships between dimensions of the patient’s

experience and interventions by the care system. Modifiable dimensions of experience according to this framework include physical symptoms (e.g., pain), psychological and cognitive symptoms (e.g., confusion), social relationships and support (e.g., family, community), as well as spiritual and existential beliefs (e.g., sense of purpose and meaning). Similarly therapeutic targets were identified by nurse theorists Ruland and Moore (1998) in their theoretical model of a peaceful death. For these authors, the peaceful (good) death is comfortable and pain free, in which the dying person experiences dignity, respect, and closeness to significant others and those who care. According to Kring's (2006) analysis of the good death, reaching life's end "without strife, discomfort, or emotional turmoil" is the "ultimate goal of humankind," and helping patients to reach this goal is a "strength inherent to nursing practice" (p. E13). Working toward the good death in clinical care, then, is a coordinated effort integrating nursing, medical, and counseling strategies that focus on improving the dying and death experiences of patients and families, making these experiences *better* than they would otherwise be without such intervention. It is this ethos of better dying that, in essence, drives clinical action within palliative care (Mak & Clinton, 1999; Walters, 2004).

Dignity.

In her doctoral dissertation, Perry (1994) composes the following reflection based on her own memories as an oncology nurse:

The warm amber glow of a candle filters through the quiet air. In the bed covered with a patchwork quilt that she has made a middle-aged woman breaths shallow, erratic last breaths. Her husband of a quarter-century sits at her side brushing her cheeks with his stock fingers and with occasional soft kisses. Although she is unable to talk, he tells her how much their life together has meant to him and how much he will miss her. As her breathing ceases he gives her a final kiss and turns to me. Freely, I open my arms and my heart to him in his grief. I leave them alone for a moment to say good-bye. As I go, he says, "Thank-you." I smile inside, feeling privileged to have shared in the final moments of their life together." (p. 81)

This passage conveys several ideas about the meaning of a good death in the context of palliative nursing practice. The aesthetics of the scene are beautiful, warm, and inviting, and therefore create an appropriate setting to accommodate the sacred nature of what is

happening. The quilt that covers this dying woman is one that she herself has made, and therefore is a symbol of her accomplishments and a material representation of her lived life. Both her husband and her nurse offer loving presence that set a space for dying that is quiet and respectful. Her husband openly acknowledges that his wife is dying and focuses his energy and attention on saying goodbye. Although it ends in death, the story has a happy ending. As the nurse leaves the room, she smiles inside, grateful to have witnessed and participated in this dignifying experience.

Preserving dignity is a primary value of ethical nursing practice (Canadian Nurses Association [CNA], 2008a). According to Gallagher et al., (2008):

Dignity cannot be compartmentalized as but one component of nursing ethics but, rather, is inextricably connected with all of nursing practice. All that nurses do and that nursing aspires to is concerned with promoting, preserving and engaging with human worth or value. (p. 10)

Intuitively, we often understand dignity through reference to situations which are felt to be undignified. Frank (2004a) suggests that “negative cases are more consensually recognized because people feel, intuitively, that anyone’s loss of dignity threatens everyone; as that other person is treated, so I myself might be treated” (p. 207). We recognize dignity violation when our moral sensibilities are offended, when we witness another’s experience as counter to our own understanding of what it means to be human.

Dignity is also a primary value of palliative care philosophy. According to Meghani (2004) the overarching goal of palliative care is the “humanization” of the care experience (p. 159). The notion of dignity is so intricately wound together with the idea of dying well that expressions such as a dignified death and a good death are often used synonymously (Volker & Limerick, 2007). A good and dignified death is typically understood as one in which the dying person is respected, well cared for, and in control (Kring, 2006). Reference to the good and dignified death is alternatively conveyed through surrogate adjectives such as comfortable, peaceful, graceful, and respectful (Wilson, Coenen, & Doorenbos, 2006).

Nordenfelt (2003, 2004) proposes a typology that includes four concepts of dignity. These are 1) the dignity of *Menschenwürde*, a German word that refers to basic

and universal human dignity; 2) dignity as merit, where people earn recognition for their life activities; 3) the dignity of moral stature, which refers to respect from self and others for living a good life, and 4) the dignity of personal identity, most vulnerable to attack by others, which depends on various dimensions such as physical integrity, autonomy, and social inclusion. Similarly, Pullman (2004) distinguishes between basic dignity, referring to the “intrinsic worth of all humanity in which we all have a stake” (p. 172) and personal dignity, referring to context-dependent notions of moral experience that can be local to an individual or group. Pullman suggests that these two seemingly contradictory notions of dignity (universal and particular) are actually dynamically related, where “Particularist expressions of personal dignity require the universal notion to give them shape and meaning...however, the universal notion requires particularist expressions if it is to have any moral relevance” (p. 173). Dignity, therefore, is basic to all humankind but can also be fostered or eroded by external influence in individual situations (Oberle & Raffin Bouchal, 2009; Proulx & Jacelon, 2004).

In an analysis of Nordenfelt’s typology, Wainwright and Gallagher (2008) suggest that nursing should be blind to dignity of merit and moral stature, arguing that the “responsibility of the nurse is to care for the human life in front of him or her and not to make judgements of the patient’s social standing or moral character” (p.51). Although this is an important caution against discrimination in nursing care, these two types of dignity may nevertheless hold relevance in EOLC. Woods (2007) for example suggests that providing for a good death means facilitating a dying experience that is “coherent with the rest of the person’s life” (p. 34). Without discriminating or making negative judgements, nurses and other care providers can, and probably should, tailor their interactions and their care by identifying, acknowledging, and admiring the life activities (merit) and values (moral stature) of their dying patients. In these ways, nurses can contribute to felt senses of integrity amongst the dying and their families (Nolan & Mock, 2004). This is important as perceived threats to personal integrity are the basis of suffering in challenging health circumstances (Cassell, 1982; Ferrell & Coyle, 2008; Kahn & Steeves, 1986; Rodgers & Cowles, 1997).

The fictional character Vivian Bearing, a professor of English literature and late-

stage cancer patient, is the protagonist of Edson's (1999) play *Wit*. With this play, Edson creates a character who does not lose herself despite the many indignities she faces over the course of cancer treatment. The following is a scene towards the end of the play, portraying an interaction between Vivian and her primary nurse, Susie. It is in this scene that Vivian delivers her "last coherent lines" (p. 72):

(...SUSIE injects morphine into the IV tubing...)

VIVIAN: I trust this will have a soporific effect.

SUSIE: Well, I don't know about that, but it sure makes you sleepy.

(This strikes VIVIAN as delightfully funny. She starts to giggle, then laughs out loud. SUSIE doesn't get it.)

SUSIE: What's so funny? *(VIVIAN keeps laughing.)* What?

VIVIAN: Oh! It's that – "Soporific" means "makes you sleepy."

SUSIE: It does?

VIVIAN: Yes. *(Another fit of laughter)*

SUSIE: *(Giggling)* Well, that was pretty dumb—

VIVIAN: No! No, no! It was *funny*!

SUSIE: *(Starting to catch on)* Yeah, I guess so. *(Laughing)* In a dumb sort of way. *(This sets them both off laughing again)* I never would have gotten it. I'm glad you explained it.

VIVIAN: *(Simply)* I'm a teacher.

(p. 73-74)

In this brief narrative exchange, Susie laughs at herself and shares a humorous moment with her patient. She further adopts a student role and thereby allows Vivian to step-into-herself as teacher, fostering her dignity. In an interview and participant observation study with hospitalized elders, Jacelon (2004) found that sense of personal dignity is a dynamic construct that was strongest for participants when "their behaviour, sense of their own value and other people's actions that conveyed their worth agreed" (p. 552). Thus, there is an important role for nurses in supporting dignity through the relational contexts they create with their patients. Nurses help patients to achieve dignity in dying through pain and symptom management, hygiene care, active listening, attending to family member needs and interests, and fostering hope (Wilson et al., 2006). According to a phenomenological study with patients, families, and healthcare providers at a hospice inpatient unit in the United Kingdom by Duarte Enes (2003), dignity in EOLC is indeed fostered through relationship and is influenced by how well one is heard and understood, how positively one is perceived

(by self and by others), how much control one has over decisions, body, and what is happening, and the degree to which one's needs are met, rights are respected, and space and privacy are provided for. Dignity is therefore both a self-directed and other regarding value (Gallagher, 2004) that absolutely depends on interpersonal relationships (Anderberg et al., 2007; Jacelon, 2004; Jacelon et al., 2004; Street & Kissane, 2001). Care that conserves dignity at the end-of-life therefore is care that is delivered with sensitivity and respect toward the other's experience (Chochinov, 2002; Chochinov et al., 2002; McClement et al., 2004). The clinician who strives to foster dignity in EOLC works toward an ethic of compassionate engagement (Pullman, 2002) and is critically reflective about how his or her own attitudes and behaviours toward care recipients affect the care experience (Chochinov, 2007). Through dignity conserving care, caregivers create safe spaces that challenge the conventional wisdom that limited functional ability and reliance on others in situations of illness is somehow deviant and intrinsically undignified (Shirley, 2007; Stanley, 2004). Rather, dignity can be promoted in EOLC through a relational ethic that, for example, affirms a failing body and reliance on others as a developmental progression through life and toward death (Byock, 1996). Dignity conserving care fosters humanity in dying and in so doing paves the way toward the good death.

Relationship.

I want what is in your mind and in your heart. These are the words spoken to Cicely Saunders by David Tasma, one of her early patients whom she credits as “the real founder of St-Christopher’s Hospice” (Saunders, 1996, p. 318). These words succinctly capture what dying patients need from their caregivers as they face the end of their lives. They require optimal implementation of evidence based knowledge for clinical care in tandem with genuine engagement by those who care for them; they wish to know and to be known. Saunders would later reflect that Tasma taught her “that patients facing the end of life as he was would need all the skills that could be developed, researched and taught, together with the friendship and care of the heart” (p. 318).

In the passage earlier (see page 21) by Mount (1993) that described the frustration, disillusionment, and alienation of a dying man’s daughter, the distress we

heard was not merely in reaction to the tragedy of dying but rather to the tragedy of not feeling heard, understood, recognized, or cared about. The relational disengagement and abandonment (*objectivity; professionalism*) that characterized this daughter's experience caused her to suffer, where integrity of self and other were undermined: *He is crumbling and so are we*.

The good death happens through relationship (Hall et al., 1996; Mount, Boston, & Cohen, 2007). For example, Valentine (2008) has shown that narratives of a good death involve retaining personhood through social presence. Bereaved family members in her study describe how they "struggled to preserve and affirm their dying loved ones' personhood and their relationship with them in order to try to achieve a good death" (p. 71). Similarly, Lawton's (2000) ethnography of dying in palliative care shows that terminally ill patients experience a loss of self through loss of relationship. Emerging conceptualizations of the good death construct repeatedly stress its fundamental relational nature (e.g., De Jong & Clarke, 2009; Granda-Cameron & Houldin, 2012; Kehl, 2006). Dying patients desire genuine and quality relational connection with their nurses in EOLC (Johnston & Smith, 2006). Phenomenological study with palliative care nurses shows that they recognize the imperative of "human-to-human connection" (Perry, 2009, p. 116) and that they are deliberate in their attempts to create habitable relational spaces within the time available.

Although quality of care relationships is key to the good death idea (Ternstedt et al., 2002), the institutional culture of healthcare can stifle the opportunity for relational engagement, threatening nurses' abilities to work toward the good death in practice (Hopkinson, Hallett, & Luker, 2003; McNamara, Waddell, & Colvin, 1995). Lack of personnel and lack of time encourage nurses to focus on *doing-to* rather than *being-with* care recipients. Nurses characterize these as heartbreaking situations that undermine their hope and faith in palliative philosophy (Rasmussen et al., 1997). Further, working with patients and families across interpersonal, psychological, and existential realms to achieve a good death is sometimes too overwhelming and difficult for some care providers, who choose to focus instead on the biological management of symptoms to feel as though they are making a difference. McNamara (2004) suggests that when aspects of care recipient distress do not yield to biological explanation or

management the rational order is challenged. Participants in her study commented that “of course we are all interested in the “holistic” care of the patient, but truthfully most of us don’t really know what that is or how to go about doing it” (p. 934, comment by a palliative care physician), and “we’ve stopped trying to get involved in family dynamics so much...time wasting its called...is it our business to go poking around where we are not wanted?” (p. 935, comment by a palliative care nurse) These findings do not negate the significance of a relational perspective for palliative care research and practice. Indeed, the decision *not* to engage with another is itself a relational commitment. They do show, however, that the question of how relationships are lived within EOLC is relevant and complex.

Tensions and challenges.

Evaluations of different forms of dying as good or bad are cultural constructions. Seale and van der Geest (2004) note that there is great variability across cultures and across time in perceptions of what a good death might mean, specifically with respect to certain dimensions as awareness of dying, control over the circumstances of death (e.g., manner and timing), and even over whether death itself is a medical event that requires the intervention of professionals.

Much of our current conceptions of what a good death means is informed by the eloquent and inspiring writings of health care providers who work with the dying. Byock (1997, 2002) for example offers that dying well (he prefers this term to good death) involves capitalizing on the opportunities that terminal illness affords for personal growth, self-actualization, and relationship building.

When patients themselves are asked about good death, however, their answers are sometimes much more simple, emphasizing a quick and pain free death that occurs during sleep (Hughes et al., 2008; Payne, Langley-Evans, & Hillier, 1996; Vig & Pearlman, 2004). Clark (2003) has pointed out that sufficiently thick descriptions of patients’ own views of good deaths are lacking; we do not yet have a strong understanding of what they *mean* when they reference wanting to die quickly, painlessly, and with dignity. Potential disconnects in how the good death is conceived by patients and by healthcare providers raise concerns about the tenability and moral integrity of scripts for good dying that serve as an orienting framework for our work

with terminally ill patients.

The viability of the good death concept is challenged by Lawton (2000), whose ethnography of hospice care poignantly draws attention to the disconnect between “Hollywood style deathbed scenes” (p. vi) and the “ubiquitous presence of bodily decay” (p. 77) in hospice. Other ethnographic research by McNamara (2001, 2004) shows that what can be reasonably achieved in caring for dying patients does not always match up with ideals put forward through good death philosophy and rhetoric. Gregory and English (1994) are critical of the appropriation of dignity within palliative care discourse, where “there is nothing dignified in dying” (p. 20). These last authors further suggest that suffering is the last human frontier to undergo medicalization, and that efforts to manage and control the suffering of others are oppositional to an ethic of care that should instead be based in empathy, understanding, and compassion. Sociological critique of the good death idea posits it as a mechanism of social control that imposes normative standards on the dying process and places patients themselves at risk of being labeled *good* or *bad* (Hart, Sainsbury, & Short, 1998).

According to an interview study with terminally ill patients, professional caregivers, and families pre and post bereavement, normative expectations of a good death (e.g., awareness and acceptance, open communication, living life until the end, taking care of responsibilities, and dealing adequately with emotions) may be relevant in a broad sense, however people invariably make use of such ideals in tailored and individual ways (Goldsteen et al., 2006). These authors therefore caution us to remain vigilant that “the current normative paradigm in palliative care about a good death [not] function as a reductionist and restrictive force in actual care for dying patients” (Goldsteen et al., 2006, p. 384).

An interesting reflection on these points is that while a good death and peaceful dying commonly share a similar meaning, for some a good death might not be peaceful at all. For example, while good death narratives of family members in bereavement sometimes emphasize peacefulness, others emphasize instead the dying person’s “fighting spirit” (Valentine, 2008, p. 72). McNamara (2001, 2004) reveals that palliative care providers sometimes encourage patients to express their rage right through to their dying moments, and that their constructions of a good death include patients

fighting until the end or remaining ambivalent about their fate. McNamara concludes that the good death ideal does not fit the realities of palliative care practice, and she proposes an alternative, the good enough death. She suggests this idea as a more person-focused ethic as opposed to a universal one, which can accommodate the themes alluded to in Dylan Thomas's classic poem, *Do not go gentle into that good night*. These ideas are consistent with what Stephen Jay Gould wrote in his autobiographical essay about battling a potentially lethal cancer, as cited by Gawande (2010, p. 10):

It has become, in my view, a bit too trendy to regard the acceptance of death as something tantamount to intrinsic dignity...Of course I agree with the preacher of Ecclesiastes that there is a time to love and a time to die - and when my skein runs out I hope to face the end calmly and in my own way. For most situations, however, I prefer the more martial view that death is the ultimate enemy - and I find nothing reproachable in those who rage mightily against the dying of the light.

It seems that stories of what makes a particular death good or bad will be as unique as those who live them (De Jong & Clarke, 2009; Steeves & Kahn, 2006). According to Proulx and Jacelon (2004) "since no two people share the same life story and personal values, it is not possible to develop a universal, best way to die that honors and upholds dignity for all" (p. 116). These authors go on to argue that while "we may have some general beliefs about what dying with dignity might entail...we cannot know what it means for any given individual unless we take the time to ask, listen, and understand" (p. 117-118).

In their nursing model of a good death, Ternestedt et al. (2002) are mindful of some of the above critiques. They nevertheless suggest that it is possible and desirable to put ideas of the good death to use in providing direction and structure to palliative care nursing practice. They argue that such ideas need not serve as prescriptive norms to which patients and families are supposed to adhere. Instead they suggest that nurses in palliative care can fruitfully make use of the good death concept by organizing, documenting, and evaluating their care according to such questions as: How well controlled are the patient's symptoms? How can the patient's autonomy and engagement in the care process be promoted? How have the patient's relationships to others changed? What is the patient's own self-image and how can it best be

supported? To what extent is the patient prepared for and accepting of eventual death?

While cautions about the good death as a potentially constraining construct are important, it seems possible to identify a framework for the good death that is basic enough as to have broad relevance across contexts and individual situations. In putting forward a conception of good death as providing for dignity-conserving care enacted through relational engagement, it may be possible to tailor efforts in EOLC toward meeting the personal and individual needs of terminally ill patients and their families.

Summary of Literature Review

The literature examined in this chapter reveals that delirium is a relevant and important issue in situations of terminal illness and EOLC. While most of the delirium literature in nursing and in medicine focuses on medicalized conceptualizations and approaches to management, important insights have been gained from research into the personal experiences of delirium from the perspectives of patients, families, and care providers. A relational perspective that centers the engagement of nurses, other caregivers, patients and families in situations of end-of-life delirium has the potential to illuminate the ways in which delirium affects whole-person care, a founding and fundamental tenet of palliative care philosophy.

Equipped with a preliminary bio-psychosocial understanding of end-of-life delirium, and with an understanding of good death as dignity-conserving care through relationship, it is now time to investigate the multitude ways in which delirium might relate to the fostering of good deaths for patients and families in palliative care. This is important because delirium is one of the most common issues faced by patients and families in dying, and the framework of the good death is the predominant moral paradigm through which EOLC is organized and delivered in contemporary palliative care. I am not aware of any study that has centered and explored these two ideas simultaneously. This study is therefore designed to address this gap.

Chapter 3: Theoretical and Methodological Considerations

In this chapter I discuss my theoretical and methodological approach. First, I position myself as a researcher in relation to the topic of inquiry, describe relational ethics as a guiding theoretical lens, and reflect on the ontological and epistemological moorings of this project. I then outline ethnography as the chosen methodology for this study and discuss the various methods that I used to collect and analyze data. In this chapter I also discuss issues of ethics and of methodological rigour, i.e., the ways in which I promote the trustworthiness of the study findings.

Positioning Myself

Before initiating a research study, it is helpful for the researcher to account for personal beliefs that shape the design and conduct of inquiry (Streubert Speziale, 2003). Drawing from my own clinical experience as a palliative care nurse and the literature reviewed in Chapter 2, my personal beliefs relevant to this study can be summarized as follows:

- Nursing care of terminally ill patients and their families toward the promotion of quality of life and the relief of suffering (palliative care philosophy) is a moral imperative.
- There are inherent tensions and problems with the good death idea as an action driving ethic in palliative care, but ultimately it represents a relevant framework that can alert us to what is at stake for patients, families, and care providers in EOLC situations. The relevance of the good death framework is supported through focus on basic values such as dignity and relational integrity instead of prescriptive norms that imply a “correct” way to die.
- A broadened conceptualization of end-of-life delirium that transcends its labeling as a pathological neuropsychiatric condition is necessary to account for and understand how delirious manifestations are lived, emotionally, relationally, and spiritually, in the context of EOLC.
- A good death framework that accounts for the experience and management of delirium within dedicated EOLC nursing practice has yet to emerge.

At this point, it is important to articulate another belief that I hold about the nature of nursing practice. As a researcher, teacher, and clinician, I am fascinated by the intricacies and subtleties of nursing practice. I believe that to best understand what nursing is and what it means for our society, we require inquiry into the complexities

of how nurses construct their everyday practice: how they think and reason, how they make decisions, and ultimately how they relate to the patients and families in their care. I believe that the ways in which practicing nurses create their relationships with patients and with families, achieved through processes of clinical reasoning, moral deliberation, and team discussion are more complex than most of our conventional conceptualizations acknowledge. My interest in how nurses construct their practice resembles the notion of *nursing gaze* articulated by Ellefson and Kim (2004) from their observations of medical-surgical nursing practice. Nursing gaze is the lens thorough which nurses interpret meaning and evoke understanding from a clinical situation. It is how nurses “see and read” (p. 127) their patients and is the basis for clinical engagement and action. I wonder, what is the nursing gaze in hospice care? To what extent is it informed by ideas of the good death? How does it shape the care of patients and families living through situations of delirium?

I approach this study with a reverence for the work that nurses do. In fact, I am often discouraged and irritated when I read nursing literature that situates its own contribution against taken-for-granted assumptions about the limited knowledge of the nursing workforce. In a recent online article about the physiology of pain for example, Wood’s (2008) opening statement reads: “Many nurses have a poor understanding of pain and its management, which can result in failure to treat pain effectively.” Ideas such as this, I think, marginalize practicing nurses as uninformed technicians who simply require more knowledge to better care for their patients. This creates and reinforces a divisiveness between nursing scholars as knowledge generators, and practicing nurses as users of that knowledge (Reed & Crawford Shearer, 2011). At our current moment in nursing’s history when we are advocating for increased numbers of nurses to take on advanced practice roles (e.g., CNA, 2008b), I am concerned that such divisiveness risks alienating our discipline from what I believe is most important regarding the study and practice of nursing: How can we better understand the relationships formed between nurses, patients, and families in clinical care?

Fifteen years ago, Chinn (1997) commented positively on an increasing trend that located nursing inquiry within practice contexts that have meaning for researchers and that in making these meaningful links clear we might “contribute to making our efforts

explicitly grounded in the nursing care contexts that we share” (p. vi). Current conceptions of nursing research however, seem to view knowledge development as the role of an intellectual elite who are removed from the practice context and yet somehow retain the potential to inform and even transform nursing practice in the care setting. This one-way flow of knowledge (from researcher to clinician) is implied in the discourses of evidence based practice and knowledge translation. Such discourses result in the positioning of clinical nurses as users rather than *inventors* of nursing knowledge. According to Reed and Lawrence (2008):

The contributions of caregiving nurses to the well-being of patients and the viability of healthcare systems are indisputable. Like the artisans of the past, caregiving nurses today are not recognized for their production of knowledge. In fact, within our current paradigm of knowledge development, most nurses are socialized into being users, not producers, of knowledge. (p. 423)

Rolfe (2006a) is critical of what he terms the technical rationality paradigm, in which theory is considered primary and superior to practice. Within this paradigm, clinicians are themselves culpable for the widely lamented theory-practice gap in nursing because of their unwillingness or inability to properly incorporate theory (knowledge) into their practice. This idea of theory as primary to practice is something that I have observed in discussions with others about my study. To give an example, in mentioning to a senior nursing leader that I am studying hospice care for patients with end-of-life delirium, I was asked: *Are you finding that nurses are practicing according to evidence-based recommendations?* It is interesting to me that the question is immediately whether practice conforms to current evidence, conventionally understood as *best* practice. I wonder, what might be gained by flipping the question and asking whether current evidence best conforms to the lived realities, circumstances, and constraints of situational nursing practice?

Flaming (2001a) finds the notion of research-based practice limiting because it sidelines other ways of knowing (e.g., experience, ethics) that she believes to be just as epistemologically significant for a proper understanding of the nurse-patient encounter. Her vision is for nurses’ actions to be determined by a practical wisdom that involves moral deliberation informed by the integration of general or universal knowledge with the local knowledge that is particular and specific to any given

situation. Flaming does not deny the significance of research for practice, but challenges its “*a priori superiority*” (p. 256). Practical wisdom is therefore inclusive of, but also transcends, knowledge derived from the methods of science (Benner, 2000).

This is not a study of research-based practice. I was not interested in analyzing the degree to which the practices of hospice caregivers *conform* to articulated best practices. Indeed, as described in my opening to the first chapter of this thesis, the idea for this project arose during my participation in the development of such clinical practice guidelines and out of a perceived knowledge gap regarding the contextual realities of daily palliative caregiving in situations of end-of-life delirium.

This is a study, therefore, of the ways in which hospice caregivers construct their practice with patients and with families toward the facilitation of good deaths in palliative care, with particular attention paid to situations in which end-of-life delirium is a relevant concern. This study responds to the claim made by Reed (2008) that practicing clinicians are an untapped resource for generating theoretical knowledge for nursing. The study is designed to produce what Rolfe and Gardner (2005) metaphorically characterize as *wet data*:

Wet research findings are immersed in experience, whereas dry findings are remote and detached. Wet data originate in [the] ‘swampy lowlands’ of practice, whilst dry data are derived from the ‘high hard ground’ of the laboratory and the controlled environment of the clinical trial. (p. 300)

Rolfe and Gardner argue convincingly for the importance of a nursing scholarship that is oriented toward “getting our feet wet in the search for research findings of relevance to practice” (p. 300).

Theoretical Lens: Relational Ethics

The good death is a moral construct. Nursing perspectives about the diverse ways in which people die and how we ought to respond are guided by “convictions of what is morally good” (Cronqvist et al., 2004). Therefore, employing an ethical analytic framework as a guiding theoretical lens is appropriate and necessary for a research study that centers the good death as a topic of inquiry.

In healthcare discourse, ethics is often associated with dramatic, morally ambiguous situations (Turner, 2002). Conflating an understanding of ethics with the

dramatic, however, obscures the moral significance of the ordinary and everyday issues of nursing practice (Austin, 2007; Levine, 1977). The nature of nursing is essentially normative (Edwards, 2001), whereby nurses attempt to maximize the good and minimize the bad for human beings in situations of health and illness. As Scott (2006) has observed:

This focus on the human, and the needs of our patients as humans, assumes an understanding of human being in terms of what is good and bad for the human, what will hurt, distress, and comfort the patient as human being. What is good and bad, harmful, hurtful or comfort-giving is normally seen to be part of the moral sphere of operation (p.138).

According to Fry and Johnstone (2008), we require an “ethic of intimates” rather than an “ethic of strangers” to guide moral action in nursing (p. 27). An ethic of intimates is consistent with nursing’s disciplinary commitment to foundational values such as helping others, patient centeredness, and whole-person care (Beagan & Ells, 2007). Nurses recognize, as does Josselson (1996), that “life unfolds as a kaleidoscope of relationships” (p. 1). Relationships are fundamental to our lived experiences and confirm our existence (Hawthorne & Yurkovich, 2003). Because we live our lives through relationship, constructs that anchor us to others such as family, community, and culture are important factors that shape our sense of personal integrity at the end of life (Nolan & Mock, 2004).

Relational ethics is a framework for healthcare ethics that centers the quality of human relationships as the focus of our moral attention. It is, in effect, an ethic of intimates. In a forthcoming overview of this framework as part of an anthology of nursing ethics, Bergum (2013) writes:

If relational space is the location of enacting morality, ethical considerations occur in every situation, every encounter, and with every patient. If all relationships are the focus of understanding and examining moral life, then it is important to attend to the quality of relationships in all professional practices” (p. 127)

Thus, relational ethics provides for a counter-ethic to the detachment and disengagement that are characteristic of much of modern healthcare (Schultz & Carnevale, 1996). A relational ethical understanding of nursing practice shines a spotlight on the relationships that matter to our patients and families and on our own

engagement with them in the clinical setting. A relational ethics perspective inspires us to look within the nurse-patient relationship to locate a “moral guide to nursing practice” (Hess, 2003, p. 138).

According to Gadow (1996), the existential meaning of ethical ambiguity is “the lack of a liveable story describing the good” (p.9). Gadow suggests that, for a story to be habitable, it must be co-authored by both nurse and patient through relationship. The central question in a relational ethic is: *Can we live with this?* (Abma, 2005). A relational approach to ethical decision making pushes the boundaries of traditional decision-making models, i.e., describe the problem, elucidate conflicts, identify principles, implement resolution, toward letting go of certainty and asking more basic, fundamental questions about moral experience: *What are you going through? How can I understand your experience? What is the best thing to do in this situation?* (Bergum & Dossetor, 2005)

The core values espoused by a relational ethics framework are congruent with the disciplinary perspective of palliative care nursing. The influential work by Davies and Oberle (1990), which first characterized the role of the palliative care nurse, emphasized the importance of *connection* between nurse and patient. This theme of connection included getting to know the patient in an intimate sense, sharing secrets, and giving of self. More recently, Dolores Wright’s (2002) ethnography of community hospice nursing practice emphasizes the value that palliative nurses place on connecting with patients and families as a central theme of their work. She found that nurses sustain such connection by being humanly present, being compassionate, and having a sense of humour.

A relational ethics perspective for palliative care nursing research is relevant because of its potential to draw forth the meaning and significance of phenomena which otherwise may, at first glance, appear simple or self-evident. For example, while a superficial understanding of the themes just referred to from Wright’s (2002) study (presence, compassion, and humour) is not difficult, an exploration of how these concepts are enacted within the nurse-patient or nurse-family relationship reveals depth of complexity and moral significance. Ethnographic research by Dean and Gregory (2005), for example, explores the functions of humour and laughter in

palliative care contexts. This research demonstrates that the use of humour in the nurse-patient relationship is anything but trivial. Rather, humour and laughter “lighten the experience of the final days,” “enrich caregiving relationships,” and convey “respect for human dignity and regard for the personhood of another” (p. 298-299).

In this study, I employed relational ethics as a guiding theoretical framework by focusing my interpretive and analytic attention toward questions of human relationship. As described in Chapter 2, delirium is a neuropsychiatric complication of dying, but it is also a relational experience. Also described in Chapter 2 is the idea that the good death is fostered through dignity and relationship, and that dignity itself is a relational phenomenon. Thus, the theoretical framework of relational ethics (Bergum & Dossetor, 2005) provides for a valuable perspective that encourages continuous reflection about the ways in which relationships are lived in the hospice context. For example, what is the nature of the caregiver – patient and caregiver – family relationship in this setting? How do the relationships that are formed here enable or constrain the ability to provide for a good death? In what ways does delirium affect the various relationships at stake?

Ontology and Epistemology

According to Denzin and Lincoln (2005), all research is interpretive. Researchers are human agents and their research activities are shaped by their basic beliefs about the world and how it should be studied. According to these authors, the framework that accounts for these basic beliefs, the research *paradigm*, is the “net that contains the researcher’s epistemological, ontological, and methodological premises” (p. 22).

In her analysis of philosophy of science as applied to nursing scholarship, Rodgers (2005) details the rise of British Empiricism, chronicling the influence of Francis Bacon, David Hume, and John Locke. She explains that for these philosophers objects of knowledge were elements of the external (i.e., subject-independent) and physical (i.e., material) world. Empiricism and its corresponding tenets of objectivity, truth, and reductionism, are the “building blocks” of a positivist way of seeing the world and are purported to be antithetical to the humanistic lens that is espoused by nursing’s theoretical legacy (Playle, 1995, p. 980). Positivism, a historical movement of the early twentieth century, was devoted to the “scientific exploration for truth,”

seeking to replace religion and metaphysics as the prime source of intellectual inspiration (Allmark, 2003, p. 7). Positivism was concerned with distinguishing sense from nonsense; for a statement to be meaningful its veracity must be knowable through empirical observation (Allmark, 2003). Such a philosophy reflects an ontological realism and epistemological objectivism, in which analysis of sensory data (empirics) is the only reliable mechanism by which reality can be known. Rodgers notes that empiricism is problematic for nursing in that it does not account for how we can know subjective and personal experience:

For the empiricists, such experience would have to be rendered somehow in a form that could be perceived by the senses. While it might be possible to have knowledge of facial expressions or body movements, would it be possible to have “knowledge” of happiness, comfort, dignity, or suffering? For the empiricists, such elements of human existence were not the focus of knowledge. (p. 64)

Researchers currently concerned with studying the qualities of human existence approach their inquiry in remarkably different ways. Some do model their approaches on the empiricist mode of scientific inquiry. Thus, hypotheses about concepts such as anxiety, dignity, and grief are tightly formulated and subjected to rigorous testing, resulting in *a posteriori* knowledge of these phenomena. An interesting example of a concept that has been reified through empirical inquiry is the idea of *acceptance* as a determinant of the good death. In her recent discourse analysis of acceptance within palliative care literature, Zimmermann (2012) highlights research that, rather than inquiring about people’s own subjective understandings of what it means to accept death, engaged an outside observer who determined and labelled the degree to which research participants were either accepting of or in denial about their own deaths.

Critics of approaches such as these contend that they misrepresent the nature (ontology) of humanly lived phenomena as amenable to reduction and objectification. Johnson (1999) for example writes that while an empiricist approach to inquiry is absolutely appropriate for investigations of the physical world (most of us would prefer to fly in aeroplanes designed by scientists committed to realist views of the universe), too often the methods of the physical sciences are misguidedly applied to the study of phenomena that are intra- and interpersonal. This results in a “crude empiricism” (p. 68) because the inherent complexity of such phenomena evades the

reductionism required by the traditional scientific method. By reducing and objectifying these phenomena, we mutate them and render them meaningless.

The reification of social constructs for empirical testing and measurement seems to reflect what Newman, Sime & Corcoran-Perry (2004[1991]) identify as the particulate-deterministic perspective. In this view, phenomena of concern to nursing are isolated and reduced according to their defining properties, ultimately for measurement purposes. Connections between and amongst such phenomena are orderly and predictable. Change in these phenomena can thus be manipulated by understanding the universal laws that explain the linear and causal dynamics at play. While this seems reasonable for certain physiological phenomena of concern to nursing, e.g., vital signs, blood counts, signs of biological death, an alternative perspective is necessary to understand and make sense of various other phenomena that are equally important to nursing practice. Examples of such phenomena that are relevant to my purposes here include ideas about and practices toward providing for good deaths in palliative care, the nature of nursing relationships in the hospice setting, and how certain dimensions of human experience such as quality of life, suffering, and dignity operate in this context.

Quality of life is one example of a social construct that has been the focus of empiricist inquiry. Quality of life is widely acknowledged as fundamental to the stated ethos of palliative care (e.g., Ferris et al., 2002). There are however diverse and conflictual ways to approach quality of life at an ontological level, which then affects the ways that it can be studied and known. Some nursing literature objectifies quality of life as a concept that can be standardized (consistently defined through attributes that are stable across cases) and therefore that can be measured in large samples and used as an outcome indicator for the effectiveness of nursing care. An oppositional view is that quality of life is an inherently subjective construct that is uniquely definable by the person living the life in question and is therefore knowable only by way of knowing that person as a human being (Willis, Grace, & Roy, 2008). Further, there is a general lack of critical questioning and reflection about taken for granted assumptions that underlie much quality of life research. Two challenges, for example, are about whether quality of life is divisible into discrete components and the

overwhelming conflation of quality of life with functional status (Leplege & Hunt, 1997). Several years ago, Hunt (1997) articulated uneasiness with the appropriation of quality of life by the medical establishment:

The phrase 'quality of life' has been largely appropriated by western medicine and health services research, both of which are embedded in western empiricism, where objective, quantitative and verifiable data have precedence over the subjective, the qualitative and the phenomenological. The clinical focus of much measurement has obscured the very real issues for the philosophy of Science. Surely, if the term quality of life has any meaning it must be rooted in existentialism, the values of the individual and the fluid dynamics of human attempts to cope with the exigencies of life. The impersonal constructs of biomedical and social science are far removed from the inner life of fear, love and hope, an inner life which is, moreover, constantly in flux and, often, ambiguous. (p. 209)

This philosophical and existential angst is not yet resolved. Ramsay (2011) has recently suggested that much quality of life research currently lacks a conceptual or theoretical foundation, and is not sufficiently collaborative with patients. She cautions that research adopting a “quantitative, hypothesis-driven approach” (p. 512) can risk imposing predetermined assumptions of experience onto research participants, might overestimate the significance of biomedical concerns, and often fails to invite participants to articulate aspects of their own experience that are most important to them.

The quality of life example just illustrated points to the potential pitfalls of adopting an empiricist approach to the study of lived human phenomena. Taylor (1985) has written that while there exists overwhelming temptation amongst researchers to model their studies of human behaviour on the empiricist model, “we cannot come to understand important dimensions of human life within the bounds set by this [empiricist] epistemological orientation” (p. 21). In a recent analysis of the applicability of Taylor’s ideas to the philosophy of medicine, Carnevale and Weinstock (2011) caution that an emphasis on objectivism and reductionism in health research can misconstrue the complexity and diversity of human life. These authors state that the study of human concepts, such as agency or selfhood, is incommensurate with the “mechanistic models of natural [i.e., physical world] phenomena” (p. 330).

Multiple paradigms have been articulated as appropriate orienting frames for

the planning and conduct of nursing research. Monti and Tingen (1999) suggest that scholarship in nursing is characterized by two predominant paradigms, empiricist and interpretative. Research consistent with an empiricist paradigm is performed by a detached observer (objective, value-free) who meticulously prevents personal bias from tainting the study results. The focus of empiricist research is on hypothesis testing and adheres to certain hallmark methodological concepts to ensure the reliability and validity of study conclusions, e.g., controlled conditions, random assignment of test subjects, and generalizability. By contrast, research consistent with an interpretative paradigm is performed by an engaged subject whose focus is extended contact with research participants through mutual interaction. Monti and Tingen draw on Carper's (2004[1978]) multiple patterns of knowing to identify the interpretative paradigm as a means of developing nursing knowledge that is broader and arguably more meaningful than what can be achieved through empiricism alone. The interpretative paradigm is suggested as nursing's attempt to align its methods of inquiry with the ontological foci of the discipline: holism and humanness. Unlike empiricism that is concerned with determining *the* truth about a single reality that is not context dependent, the interpretative paradigm provides a framework for asking and answering questions about the experiences of people and the meanings of these experiences. Monti and Tingen observe that these two paradigms are fundamentally irreconcilable due to their opposing ontological and epistemological views. They advocate, however, that diversity of paradigms within nursing is healthy for our scholarship and the continued evolution of our field as a mature science. They suggest that the practice of nursing is sufficiently diverse to require knowledge developed from both paradigmatic perspectives. Other leading nursing writers have endorsed the view of multiple perspectives and approaches across studies for the development of nursing knowledge (e.g., Fawcett et al., 2004[2001]).

Weaver and Olson (2006) suggest that there are four paradigms for the structure and conduct of nursing research: positivism, post-positivism, interpretive, and critical social theory. Based on an integrative review of the literature, these authors compare and contrast each paradigm and provide an analysis of the relative value and limitations of each. The crucial difference between positivism and post-positivism has

to do with verifiability. While positivism holds that external reality exists and is knowable, post-positivism holds that knowledge is only probable and never absolute. Both however are based on a realist ontology and promote the conduct of scientific inquiry that is value-free or value-neutral to reach objective conclusions. Research conducted within the critical social theory paradigm is meant to uncover taken-for-granted and hidden power imbalances inherent within social structures toward an emancipatory end-goal.

The interpretive paradigm, according to Weaver and Olson's (2006) analysis, is based on a relativist ontology, meaning that truth relates to "multiple local and specific realities that can only be subjectively perceived" (p. 462). Researchers within this paradigm develop knowledge about experience and meaning of experience that is "co-constructed between researchers and research participants" (p. 462) in a natural (i.e., lived) environment. Similarly, an emphasis on truth as comprised of multiple realities and knowledge as co-constructed is identified by Appleton and King (1997) within the nursing research paradigm of *constructivism*. Constructivist inquirers are concerned with the narrative qualities of human life and therefore generate knowledge that accumulates through experience and that is value-mediated and subjective (Guba & Lincoln, 2005).

Multiple realities.

In a classic paper by Dean and Whyte (1958) about the relative truth-value of stories told by research participants in qualitative studies, the authors challenge the idea that there is such a thing as "real belief" (p. 34). They reformulate the question about veracity of participant accounts to an invitation for researchers to instead explore what participant's stories reveal about their subjective experiences of a situation.

The relevance of such an orientation to the specific topics of good deaths and end-of-life delirium is supported thematically by the literature reviewed earlier in Chapter 2, where multiple perspectives concerning the nature of these notions can exist all-at-once. Recall, for example, that a good death might mean a peaceful death, but it might also mean dying fighting (McNamara, 2001, 2004). Delirium is a physiological condition that results from metabolic disturbance and hypoxia (Harris,

2007) but it might also be interpreted as a fearful or combative response to the recognition of impending death (Brajtman, 2005a).

Knowledge as co-constructed.

I agree with Playle (1995) who finds confusing the idea of “detached objective rigour” as a standard for knowledge development for a discipline (nursing) that is ultimately focused on “empathic involvement and understanding” in practice (p. 982). Playle observes that in nursing practice, “subjective experiences of both the nurse and patient are given priority, as well as the way in which the individuals in the context of the encounter give definition and meaning to the situation” (p. 981). My own understanding of our discipline is that focus on the unique relational encounters between nurses, patients and families represents our very ontology; the nature of our being as a collective professional discipline is grounded in the relationships that we form with those we care for (Wright, Brajtman & Bitzas, 2009). Therefore, I am inclined to design and conduct nursing research that is faithful to such a perspective. Ultimately my study is a relational inquiry that hopefully has the potential to illuminate and inform relational practice.

As a nurse, I believe that knowledge for healthcare practice is indeed constructed through attention to the subjective experiences-as-lived of illness and health, for patients, families, and caregivers alike, as well as the meanings that all of these people attribute to their experiences. My constructivist approach is compatible with the interpretive paradigms identified by Monti and Tingen (1999) and by Weaver and Olson (2006).

A constructivist epistemology for palliative care.

Palliative care nursing is enacted through human relatedness (Krisman-Scott & McCorkle, 2002; Wu & Volker, 2012). Research methods that are commensurate with a relational ontology and engage a transactional epistemology are therefore appropriate to study the lived realities of daily palliative care nursing practice. Further, palliative care is defined by an ontology of holism that considers the self to be a unity of biological, psychological, social, and spiritual dimensions. It is therefore fitting to develop knowledge for palliative care through a methodology that joins the scientific and the sacred, focusing on “the experiential, the embodied, the emotive qualities of

human experience that contribute the narrative quality to a life” (Guba & Lincoln, 2005, p. 205). Indeed experiences of dying and death represent, for many of us, our most sacred narratives (Berry & Griffie, 2006; Gelfand et al., 2005; Marantz Henig, 2005).

Although originally pioneered in response to concern regarding the medicalization of dying (Clark, 2002), there is skepticism that palliative care, as an emerging subspecialty of medicine, is itself in danger of being overwhelmed by a predominantly biomedical focus (Bruce & Boston, 2008; Kearney, 1992; Marantz Henig, 2005). This concern is particularly relevant when we consider that much of the literature on delirium at the end-of-life reinforces a dominant discourse of this condition as a neuropsychiatric complication of dying, while neglecting broadened perspectives that more fully account for the emotional, spiritual, and interpersonal dimensions of this phenomenon. In order to generate theory that faithfully informs nursing practice, a multitude of methodological frameworks are needed to answer questions not only about diagnosis and treatment but also meaning and experience of health phenomena (Fineout-Overholt, Melnyk, & Schultz, 2005). In tandem with quantitative health studies, qualitative inquiry is vital for the development of healthcare practice because it “enables an understanding of phenomena that is frequently not possible within a framework of [positivist] scientific explanation” (Macdonald & Carnevale, 2008, p. 3). According to Kleinman (1992), an ethnographic approach to the study of illness and care expands our gaze beyond the biomedical and enables examination of the interactions between social, psychological, and physiological dimensions of health phenomena. This type of inquiry recognizes that people everywhere have something *at stake* within the local worlds they inhabit (Kleinman 1999). By questioning what matters for individual people as stakeholders within a given context, i.e., “What matters most in the mundane and extraordinary transpersonal details that bind and define us through relationships, work, and the close politics of a particular place” (Kleinman, 1999, p. 70), we can develop important and useful knowledge about the ways in which people experience their everyday social world.

Ethnography

The word ethnography means the writing of culture (Atkinson, 1992a; Oliffe, 2005). It is distinguishable from other methodologies in its grounding in the “culture concept,” seeking to understand how people experience a cultural system (Aamodt, 1991, p. 44). Culture represents the shared beliefs, values and practices (Freund & McGuire, 1999) that can be inferred from the words, actions, and artifacts of a group (Spradley, 1980). It is a communal system of meaning that is learned and propagated amongst people (Chan, Macdonald, & Cohen, 2009). Culture guides our view of the world and structures our experiences (Polit & Beck, 2004). Culture is all around us; it represents the “webs of significance” in which we are all suspended (Geertz, 1973, p.5).

As a qualitative health research methodology, ethnography serves to generate holistic cultural portraits (Creswell, 2007) of health and illness experience and the care that is provided in response to such experience (Kleinman, 1992). As cultural analysis, ethnography is an interpretive inquiry that seeks underlying meanings behind what is observed (Geertz, 1973). Arguing for the value of such inquiry to palliative care research, Chan et al (2009) suggest that:

...examinations of different settings using an expanded view of culture allows a better understanding of the context in which people are dying, including: staff attitudes, beliefs, and common practices; the way the physical environment is organized; and the meaning of events and occurrences. (p. 122-123)

Ethnography integrates description with interpretation of social organization and culture, generally consisting of the following features: 1) the study of people in an everyday context; 2) multiple methods of data collection; 3) an initially unstructured, flexible research design whose structure solidifies as the research unfolds; 4) a small-scale focus (e.g., a single setting) to facilitate in-depth examination of the phenomena of interest; and 5) an approach to data analysis that involves a context sensitive interpretation of the meanings, functions, and consequences of human behavior and institutional practices (Hammersley & Atkinson, 2007). As a research methodology, ethnography is both interpretive and systematic (Robinson-Wolf, 2007) and is anchored by the basic belief that behaviour and experience can only be understood through concomitant examination of the context in which they occur (Robertson &

Boyle, 1984). According to Savage (2006), it is “the way in which ethnography makes links between the micro and macro, between everyday action or interaction and wider cultural formations through its emphasis on *context*, that most clearly distinguishes ethnography from other approaches” (p. 385, original emphasis).

Ethnography as a research methodology has proven valuable in demonstrating complex social processes at work within healthcare culture (e.g., Seymour, 2000), and making visible the work of nurses in clinical care (e.g., Robinson-Wolf, 1988). Some examples of the application of ethnographic methodology to EOLC nursing research are Kayser-Jones’s (2002) study of death and dying in the nursing home setting, Dolores Wright’s (2002) study about the role of community hospice nurses, and Stajduhar’s (2003) study on the experience of end-of-life family caregiving in the home. Collectively, this body of work moves beyond a common tendency within qualitative health research to privilege narratives of individuals, generating deeper understanding of the social, relational, and political forces that shape the experience of care providers and care recipients in EOLC.

The overarching goal of contemporary ethnography is to “describe, interpret, and understand the characteristics of a particular social setting with all its cultural diversity and multiplicity of voices” (Holloway & Todres, 2003, p. 348). The methods of ethnography, which include participant observation, interviews, and document analysis, are implemented through prolonged fieldwork during which the researcher is immersed in the environment under study. The ethnographic framework therefore provides for a natural triangulation of methods to arrive at as thorough and holistic an understanding as possible (Maxwell, 2005). Ultimately, my study of hospice care is an inquiry into the facilitation of good deaths in palliative care, particularly in situations of delirium, with attendant focus to the contextual (cultural) forces that shape the relationships at stake.

The nature of ethnographic understanding.

The primary strategies of ethnography, which center on observation of events in a social setting, have been compared to interview methods with respect to the relative contributions each make in constructing social knowledge. Becker and Geer (1957) attributed to participant observation the value of producing data of the most *complete*

form. It is in the ability to observe reality as it unfolds that Becker and Geer conferred upon participant observation an inherent methodological advantage over interviewing. Shortcomings of methods based solely on narration, they argued, exist both because the researcher can only expect to attain a partial interpretation of events that are recounted (i.e., because of cultural language constraints) and because participants themselves are flawed narrators (i.e., there are some matters participants are unable to talk about). Becker and Geer's arguments rest on an important epistemological perspective regarding the relationship of the knower to what is known. For these authors, events merely *happen*; they exist 'out there' and can be seen and described (apprehended) by an astute observer. Participants are cast as relatively helpful/unhelpful agents in facilitating the description and explanation of such social events.

The realist nature of Becker and Geer's ontology and the (over)confidence in their authority as authors are reflected in their statement that "participant observation makes it possible to check description against fact" (p. 31). Such an assertion presumes a correspondence theory of truth that implies a direct relationships between what is observed and what is (Polifroni, 1999) and denies the active role that participants, as well as researchers, play in shaping reality through the social situation that *is* the research encounter. Becker and Geer were not wrong, however, in their suggestion that participant observation is advantageous in creating understanding of a more holistic nature than interviewing alone (Atkinson, Coffey, & Delamont, 2003). It is reasonable to assert that the study of people's actions, interpreted through attention to the context in which they are performed, is likely to be more revealing than decontextualized verbal accounts (Oliffe, 2005).

Atkinson et al (2003) provide thoughtful direction for reconciling the belief that ethnographic understanding provides a certain 'value added' without endorsing an inherent methodological privilege of observation over interviewing. For these authors, ethnographic understanding *is* a more complete form of knowledge. Such knowledge is achieved, however, not from simply seeing things happen but rather through the researcher's active dialogical and participatory engagement with the environment under study. Atkinson et al. advocate a *return to participation*, whereby researchers

commit to a comprehensive understanding of social life in all its complexity, “it’s detail and the slowness of its unfolding” (p. 114). Seen this way, ethnography is justified as an appropriate research approach to clinical nursing problems, without denigrating the value of interview methods in contributing to knowledge. Indeed, from this perspective, interviews *and* participant observation become equally important methods of enacting the social engagement required to arrive at a truly ethnographic understanding.

In this ethnography, I entered the culture of hospice care and committed to an openness to see, hear, participate in, and understand the realities as lived by members of this caregiving community. Through engagement with the hospice community I strived to understand the ethos of this setting. According to Geertz (1973), “A people’s ethos is the tone, character, and quality of their life, its moral and aesthetic style and mood; it is the underlying attitude toward themselves and their world that life reflects” (p. 127). The main method through which the data were generated was therefore my ‘hanging out’ (engagement) with hospice caregivers, with patients, and with families, searching to discover the underlying tones, character, and mood of this place. I entered the hospice with two broad curiosities: the notion of good death and the nature of end-of-life delirium. Beyond these broad curiosities, I stepped back and attempted to allow the landscape of hospice to reveal itself. Over the course of repeated field visits I engaged with hospice caregivers as they went about their everyday work. I sat with them in the nursing station as they talked about their practice and about their patients. I accompanied them to patients’ rooms as they provided care and supported family members. I had many unstructured conversations with patients and with families that centered their experience, their priorities, their perceptions, and whatever else they were most interested in talking about. I participated in discussions and meetings in which team understandings of particular cases were elaborated and refined. I shared many meals with hospice caregivers, as we reflected together on the meaning, significance, and difficulties of their work. I also attended events within the hospice such as memorial services and a volunteer meeting. Further, I attended relevant events outside of the hospice, such as fundraisers, continuing education activities and conference presentations given by hospice caregivers. Participation in such events

enabled a stronger understanding of the values that underlie hospice caregiving practice and also of the relationships the hospice holds with the wider community. My approach was designed to be consistent with Atkinson's (1992a) assertion that the ethnographic field is not discovered but rather is constituted through the interactions between researcher and participants. The "field" as portrayed in this thesis has been constructed: 1) by my own gaze, 2) by my ability to conceive and produce a "text-of-the-field," and 3) by my interpretations and contextualizations (Atkinson, 1992a, p. 9).

Setting

The setting chosen for this study, with which neither I, nor any of my thesis committee members, had any pre-existing relationship, is a nine-bed palliative care facility (hospice) located in a suburban community of eastern Canada. It is a non-profit charitable organization; the provincial government provides approximately one third of the operating funds, based on a fixed monetary allowance that is accorded for every designated palliative care bed in the province. The remainder of the budget is obtained through fundraising. Patients stay and receive care here free of charge, though they are responsible for the costs of their own medications and medical supplies, as they would be if they were living at home. These costs are partly covered through personal insurance plans or the default (compulsory) public insurance plan. Despite this, a very small minority of patients (less than five percent) cannot afford their personal contributions, i.e., deductibles and co-insurance payments. In these cases, the hospice assumes these costs on behalf of the patient, through what is referred to as the "Good Samaritan Fund."

Hospice caregivers and other staff include registered nurses and registered nursing assistants, physicians, patient care attendants, counselors (psychology and social work) over 200 volunteers (including pastoral care and music therapy), senior administrators, as well as fundraising, housekeeping, maintenance, and kitchen personnel. Nurses working at the hospice are not unionized. An organizational chart of this hospice is presented in Figure 1.

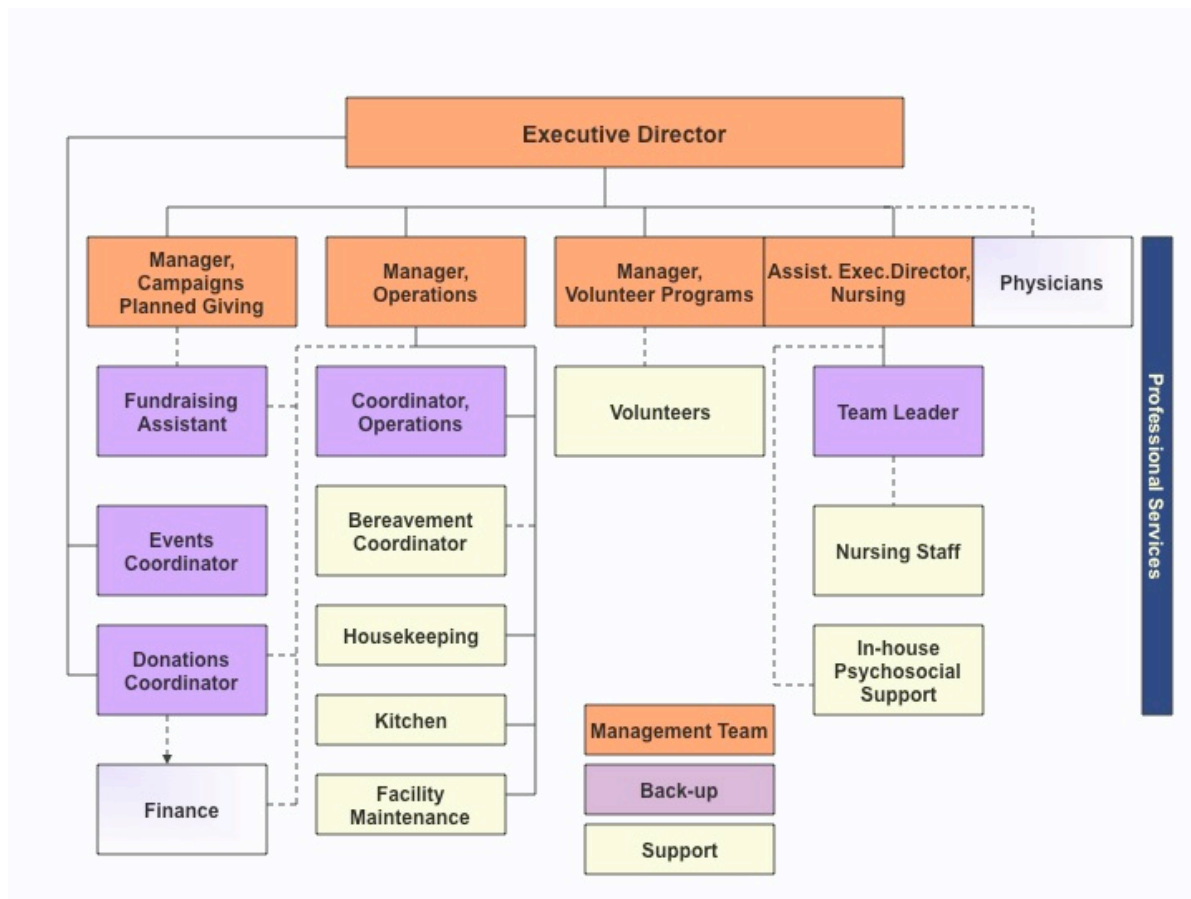


Figure 1. Hospice Organizational Chart

The nursing director (Assistant Executive Director) and nursing team leader work together in the hiring of caregiving personnel, i.e., nurses, nursing assistants, and patient care attendants. Approximately two thirds of the nurses here are registered nurses, while the other third are registered nursing assistants. Of the registered nurses, approximately one third have a bachelor's degree in nursing, while the other two thirds have college degrees.

The hospice has been open for ten years. There are currently eight nurses who have worked here since that time. During the period I conducted fieldwork, two nurses were hired (one registered nurse and one nursing assistant). One other nursing assistant had worked here for less than two years. With the exception of three bachelor's prepared registered nurses, none of the hospice nurses had any palliative care experience prior to starting here. Four hospice nurses, as well as the two nursing leaders (nursing director and nursing team leader) currently hold specialty

certification in hospice palliative care nursing through the Canadian Nurses Association.

All of the patients cared for in this facility are living with incurable, terminal disease and are admitted when they have a prognostic estimate of three remaining months of life or less. To be referred for admission here, the patient's health care provider completes a referral form that asks for details of the patient's diagnosis, treatments received, current symptoms, current medications, other medical history, and an estimated life expectancy. Other information requested concerns the patient's current level of understanding about diagnosis and prognosis, degree of family involvement, and whether the patient's expectation is to die at home or at an institution. This form is made publicly available on the hospice's website, and is used across settings, whether the potential patient is in hospital or in the community. The nursing leaders maintain a list of patients who are referred and are appropriate for admission. They regularly review this list, checking in on the status of these patients to determine the best time for their admission. Patients are not admitted according to the order in which they are referred. Rather, decisions as to who is offered a bed are based on the health status of the potential patients. The most severely ill and/or imminently dying patients are prioritized for admission, as are patients who are coming from home or from a hospital emergency room.

The average length of stay (from admission to death) is less than two weeks, with approximately fifty percent of patients dying within five days. Over the course of one year the setting admits between 200 and 250 patients. Preliminary conversations with nurses working at this hospice before beginning the study confirmed that end-of-life delirium is a relevant and common clinical phenomenon here.

I need to state upfront that I recognize that a freestanding hospice is a unique care environment that is not representative of the contexts in which most patients receive EOLC. Indeed, the proportion of Canadians who die in such facilities is extremely small (Wilson, Truman, et al., 2009). My choice to study the relationship of end-of-life delirium to good dying in this setting however was purposeful. I reasoned that of the various options for an in-depth examination of end-of-life caregiving, hospice was likely to represent a context in which the enactment of a palliative care

ethic would be most visible. Therefore I hypothesized that if a good death is at all possible in situations of end-of-life delirium, it would be within the hospice context that such a possibility would be most discernible. Elucidation of the relationship between delirium and good dying as manifest within hospice, then, might provide for some interesting reflections about practice in different care contexts in which greater numbers of Canadians die (e.g., acute care, long-term care, in-hospital palliative care).

Participants in this study included all people who comprise the hospice setting. I focused predominantly on the nurses and other hospice caregivers, as my main interest had to do with practices of hospice caregiving and construction of clinical nursing practice. Select patients and families were however also included as participants, as ethnographic engagement and analysis is impossible without paying attention to all the players that comprise the social landscape of the studied environment. Unlike a care unit in a University teaching hospital, the nature of this setting as a freestanding facility meant that caregiver participants represented a very stable pool of people; very little turnover occurred over the course of fieldwork. With the exception of four people, all of the hospice caregivers I interacted with over the course of this study were female. Feminine pronouns are used throughout this thesis when I am referring to individual hospice caregivers.

Fieldwork

Fieldwork for this study consisted of three broad activities: participant observation, interviews, and analysis of documents and artifacts. A summary of each of these three methods is depicted in Table 1:

Participant Observation	Interviews	Document and artifact analysis
15 months / 80 visits / 320 hours (Fieldnotes)	28 formal, audio-recorded (Transcribed)	Care documentation, protocols, pamphlets, thank you cards... Medical technologies, furniture, photographs...

Table 1. Summary of methods

I started fieldwork in June 2010. Over a period of fifteen months, I visited the hospice 80 times. During these visits, I engaged three broad methods of data collection: participant observation, interviews, and analysis of documents and artifacts. In employing multiple modes of data collection in the same study, my goal was to explore my research question and objectives from “multiple perspectives and vantage points” (Russell & Gregory, 2003, p. 39). Each of these methods is described below.

Participant observation.

I conducted a total of 320 hours of participant observation that spanned the entire twenty-four hour day (i.e., of the 80 visits, 58 included time spent during the day nursing shift, 43 included time spent during the evening nursing shift, and 10 included time spent during the night nursing shift).

Ethnography is “typified by the priority placed on gaining an emic perspective” (Savage, 2006, p. 384-385). For this reason, the hallmark method of ethnography is participant observation, where the researcher seeks to understand how various players involved in a social setting “think, believe, and behave” (Brink & Edgecombe, 2003, p. 1029) and ultimately, “how they understand their world” (Delamont, 2004, p. 218). Participant observation is a means to study human relationships, patterns, events, and environmental context (Robinson-Wolf, 2007).

The work of nurses in hospice care represents “the subdued and sometimes seemingly hidden threads that constitute the background upon which the design [hospice] depends” (Krisman-Scott & McCorkle, 2002, p. 32). Therefore, a research method that involves active engagement through prolonged participation and observation by the researcher was ideally suited to capture such subtleties of practice. Further, a central focus of this study concerns how delirium care is provided in a way that might foster the good death, particularly through maintenance of dignity and relationship. Participant observation is a well suited method for identifying how dignity is either promoted or eroded in situations of everyday practice. For example, repeated and prolonged observation by Perry (1998) has elegantly shown that nurses who physically touch others in a caring way do so out of respect for patients as people of inherent moral worth. Conversely, through immersion in nursing home culture,

Kayser-Jones (2002) has described how the dignity of elderly residents is threatened through neglectful care practices such as poor pain management and failure to assist with basic activities of daily living (e.g., help with meals or getting out of bed). Participant observation is particularly appropriate to not only identify such dignity enhancing/dignity stripping moments, but more importantly to interpret these from a systems perspective that takes into account how care practices and activities are culturally embedded. Nursing care practices of respect or neglect, for example, are best understood through attention to the broader context in which they occur. Gallagher et al. (2008) give the example of patients receiving inadequate care in situations of nursing shortage. In such cases these authors remind us that a thorough analysis understands such disrespect to be “institutionalized” (p. 9) and acknowledges the difficulties nurses face in overcoming this.

During ethnographic fieldwork the setting is sampled in a holistic way, focusing on different types of participants and making observations in all possible locations and at all times of the day and night (Delamont, 2004, p. 223). Participant observation in this study was planned around the three dimensions of time, people, and context (Hammersley & Atkinson, 2007). Planning around *time* involved decisions about when to observe, e.g., day, evening, and night shifts, change of shift, weekly team meetings, weekdays and weekends. Planning around *people* involved decisions about who to observe, e.g., which hospice caregivers, which patients, and which families. Planning around *context* meant paying attention to differences in observation between various locations within the research setting, e.g., patient rooms, hallways, nursing station, conference room. Observation is not a passive exercise. Rather, the participant observer continuously raises questions about what is being observed (sights, sounds, smells, events, verbal and non-verbal exchanges, interaction recordings, descriptions of physical organization, descriptions of human organization) and explores possible relationships between these observations and other types of collected data (Allan, 2006; Edvardsson & Street, 2007; Robertson & Boyle, 1984).

Initially, I occupied an “outsider” position vis-à-vis the research setting, gradually progressed toward more of an “insider” role (Creswell, 2007), and then moved back and forth between these. Both of these positions (insider / outsider) are

epistemologically significant (Allen, 2004), as each allowed for collection of data and interpretations of a different sort. My goal throughout was to make the strange familiar as well as to make the familiar strange (Atkinson et al., 2003). Moving progressively into more of an insider role was enabled after several field visits during which I negotiated relationships with hospice caregiver participants, each of us becoming increasingly familiar to the other. To then move back to a more outsider position, I would sometimes stay away from the hospice for extended periods of time (several weeks). This allowed not only time to reflect on preliminary analyses and to think through emerging conceptualizations, but also to step into a more distanced (outsider) position upon my return.

As a *participant* observer, I did not perform any activities that are part of the legally defined role of the nurse (e.g., giving medications, administering treatments). I did participate however, whenever appropriate as judged by the hospice caregiver, the patient or family, and myself, in non-legally defined roles as might be performed by a volunteer. Such activities included feeding patients, bringing family members tea or coffee, changing beds, and stocking supplies. I also helped with certain aspects of patient care in the presence of a nurse (as a volunteer here would do), such as turning and positioning patients and assisting with hygiene care. The importance of such participation is twofold. First, it facilitated a move *into* the research situation to allow for the generation of data that would not otherwise be possible from a position of detached onlooker (Roper & Shapira, 2000). Second, it facilitated development of mutually respectful relationships with staff research participants (Seymour et al., 2005). Many times during my time at the hospice I would ask “Can I help with anything?” and sometimes I would be given something to do. Such participation also enabled a respectful relationship to develop with patients and families. They could see that as a student researcher I was not just committed to my own research interests (as would be communicated were I to merely lurk as a fly on-the-wall) but rather that I was genuinely interested in their experiences and happy to assist them in any way that they might find most helpful.

At the end of each field day, as well as available moments within the day while at the hospice, I wrote field notes about what I was observing and the possible meanings

of these observations. Field notes constituted a primary source of data for analysis. I also wrote reflective memos to myself, chronicling my developing thoughts, feelings about, and reactions to what I was observing.

When in the hospice, I frequently wrote fieldnotes in full view of the participants. I would sit at a table in the nursing station, or at tables in common areas, and write fervently. This decision to be open about my field journaling was both for methodological and ethical reasons. Methodologically, it was often important for me to be able to fully think through an interaction or a situation by journaling about it 'on the spot' before being able to engage in subsequent observations. When recent observations were not soon recorded in some way I was unable to move on and open myself to seeing, hearing, and participating in whatever was most interesting in the moment, as I remained preoccupied with not forgetting what had come before. Ethically, my visible journaling during my time in the hospice reminded participants that I was there as a researcher, and that I was indeed recording details about my observations and experiences. I believe this was an important part of respecting informed consent for observation, as over the course of prolonged fieldwork participants may forget that they are being observed (Emerson, Fretz, & Shaw, 2011).

Interviews.

A strength of an ethnographic approach is in the identification, through observation, of behaviours that are internalized and therefore performed without full awareness by participants. The meanings of these internalized behaviours can then be further explored through interviews (Brink & Edgecombe, 2003). Interviews allow the researcher to understand the ideas, thoughts, and memories of participants in their own words, rather than the words of the researcher (Reinharz, 1992). Through interviews, the ethnographic researcher strives to "explicate the ways that people understand and account for their day-to-day situations" (Maggs-Rapport, 2000, p.220).

The interviews in this study were both informal and formal. Informal interviews included the countless dialogues I had with hospice caregivers, patients and families. These were casual and conversational in tone yet also purposeful. They served to further my understanding about the practices in operation, where for example I would ask specific questions about what I was observing as I was observing it. The content of

these dialogues were usually recorded in my fieldnotes immediately after they occurred. Alternatively, I would make *jot notes*, which provided an outline of the main points of the interaction, with detail to be filled in later. Full fieldnotes based on jotnotes were written within twenty-four hours, either immediately after leaving the hospice or the next morning before returning.

Formal interviews were scheduled conversations with hospice caregiver participants. These were audio-recorded and transcribed verbatim for analysis. They took place in private locations within the hospice setting, e.g., library with door closed, upstairs conference room, or private offices. The interview questions were determined from evolving hypotheses that emerged throughout my immersion and engagement during fieldwork. While I entered the hospice in June 2010, my first formal interview was more than three months later in September 2010. Thus, I waited until my understanding of this setting and my preliminary hypotheses about delirium and good death were sufficiently developed to enable a truly in-depth conversation with research participants. This approach of conducting interviews based on the analysis of participant observation data has been used successfully in previous ethnographic research (e.g., Allan, 2006). The content of my interviews, then, enabled participants to really reflect on specific questions about the nature of their work, about delirium, and about good deaths. These reflections proved more insightful, I believe, than would have been possible through a conventional qualitative interview using predetermined questions and conducted devoid of historical context and relationship between the researcher and the participant. Further, because I knew many of the patients and families and because I had been present with these caregivers during their work, our conversations about care practices were personal and specific. We talked about specific cases and specific situations. Because the participants knew me and knew that I was aware of the basics of their practice, our conversations were less focused on their describing their work to me than on their *interpreting* their work *with* me.

A total of twenty-eight hospice caregivers participated in formal interviews. This sample of participants included: registered nurses (n=6), registered nursing assistants (n=5), nursing leaders (n=2), patient care attendants (n=3), physicians (n=4), psychologist (n=1), social worker (n=1), volunteers (n=5), and volunteer

coordinator (n=1). Each of these participants was interviewed once. One of these interviews occurred over the course of two days, as this participant was called away during the interview to attend to an urgent care situation. The average interview length was approximately 45 minutes. Appendix A contains a list of some of the common questions that I posed during these interviews.

Documents and artifacts.

Written documents and material artifacts are important sources of data that are often overlooked in ethnographic research (Hammersley & Atkinson, 2007). While qualitative research tends to privilege verbal data, the researcher gets closer to the storied experience of a culture by paying close attention to the material objects that both populate and shape the setting studied (Sandelowski, 2003). Nursing ethnographers are encouraged to be creative when imagining what documents and materials might be relevant to their analysis of the field (Roper & Shapira, 2000).

Over the course of fieldwork, I read various sources of caregiver documentation (e.g., progress notes, weekly team meeting sheets, report boards, and grief assessment forms) that were completed by hospice caregivers during their practice. Learning about how patients and their families are written about by hospice caregivers was an important source of understanding how care providers conceive of their roles, organize their care, and construct their relationships.

Other documentary sources proved valuable for illuminating the overall context of hospice culture. For example, documents designed to be read by hospice caregivers themselves (e.g., policy on care of the body after death) provided insight into some of the overarching values that guide care in this setting. Documents designed to be shared with patients and/or families, meanwhile, provided an interesting source of reflection about some of the determinants of hospice caregiving relationships. For example, the consent form specifying *conditions of admission*, which patients and/or families read and sign upon arrival at the hospice, clearly identifies the hospice's mandate and focus of care as oriented toward the end-of-life. Written information about the dying process identifies for families what they might experience as they witness their loved one's deterioration and death. Consideration of documents such as these centered questions about how the people in this setting use them: Are they used? What is their use? When

are they used? How are they used? What is the consequence of their use? This questioning led to interesting hypotheses about the nature of the relationships hospice caregivers build with patients and with families. Further, hypotheses as to the impact of these relationships for all involved was informed by the reading of thank-you cards and letters, written by families after patient death and displayed by hospice caregivers in the nursing station. Such hypotheses were further developed, refined and explored through observation and interviews and through iterative processes of data generation and data analysis.

Finally, continual attention was paid to material artifacts within this setting, again with specific focus as to their *use* and their implications for hospice caregiving relationships. Such artifacts included: various medical technologies such as for medication administration and oxygen delivery; the clothing patients wear and the towels, blankets, face cloths, draw sheets and bed linens that they use; the furniture in the patient rooms and common areas as well as decorative items such as plants, artwork, personal photographs and paintings.

Data Analysis

Analysis is not a discrete phase of the ethnographic process, but rather is integrated throughout all aspects of the research. Ethnography proceeds in a series of “loops,” where at each step of the journey the researcher reflects on and revisits earlier steps (Delamont, 2004, p. 223). The analytic process in ethnographic research therefore integrates the ongoing development of hypotheses during fieldwork that guide subsequent data production (Geer, 1964). In this way, the researcher continuously searches for evidence that either supports or complicates evolving theoretical formulations (Mackenzie, 1994).

Spradley (1980) describes the cyclical nature of generating and analyzing data that occurs in an ethnographic project (Figure 2). In his view, *asking ethnographic questions* refers not only to the research questions, but also to the questions that are asked by the researcher as he or she participates in fieldwork. Spradley contends that questions and answers are not separate elements of human thinking; questions always imply answers and statements of any kind always imply questions. This is regardless of whether both are explicitly stated. The ethnographer’s task is therefore to discover

both the questions and answers within the social situation being studied. Analysis thus involves questioning of field observations: What does this mean? What is this in response to?

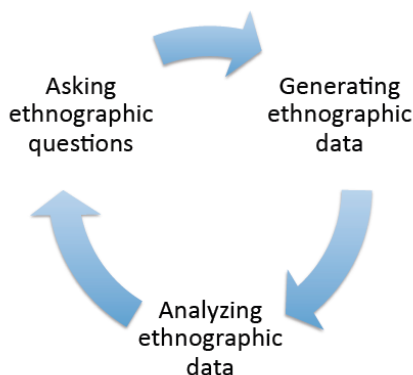


Figure 2. Inspired and adapted from Spradley’s (1980) “ethnographic research cycle” (p. 29)

Analysis pervaded all aspects of this research. The reading of early fieldnotes informed the planning of subsequent observations. Eventually, a closer reading of a large amount of participant observation data (three months of fieldnotes) informed the development of initial interview guides. In turn, analysis of early interview data informed the development of subsequent interview guides and further oriented ongoing participant observation.

I did not follow a rigid step-by-step approach to analysis. I agree with Atkinson (1992b) that strategies for qualitative data analysis that rely on fragmentation that decontextualize and then reconstruct field data risks falling out of touch with the realities of the field and can reinforce a positivist reading of the data. Rather, I followed the advice of Appleton and King (1997) that the constructivist inquirer does not follow a formulaic analytic process but rather works diligently in thoughtfully exploring the data as he or she attempts to come to grips with it all. My overall goal was to become genuinely immersed in the data to be able to reflect on such broad questions as: *What is going on here? What is the story here?* I regularly listened to the audio-recordings of my formal interviews while walking, driving, or on the subway (using earphones and a

password protected playback device). I transcribed interviews myself and while transcribing made extensive notes about what I was hearing, and how it compared to what I had heard or seen before. These notes often took the form of coding toward theme identification, but were also sometimes methodological reflections, e.g., *I shouldn't have asked that, next time ask this instead.*

Fieldnotes and interview transcripts were read, reread, and read again. Initially, analysis consisted mostly of open coding and the writing of general memos. These memos were notes to myself about what the data might mean and thoughts about the data that were to be followed up on through subsequent fieldwork and/or targeted literature searches. Eventually, analysis moved toward more focused coding and the writing of integrative memos, which were notes to myself about diverse segments of data grouped by common idea (Emerson et al., 2011). Integrative memos were informed by the constant comparisons I was increasingly able to make as I achieved intimate familiarity of the data as a whole (Appleton & King, 1997).

At all times in the analysis process, I considered the relationship between the data's manifest content (what was written) with its latent content (what it might mean) (Graneheim & Lundman, 2004). I questioned the meaning of people's actions within the hospice environment: what are they doing, and why? (Hammersley & Atkinson, 2007) The analytic process was oriented toward developing a thick description (Geertz, 1973; Mueke, 1994) of the hospice culture. Thick description is an anthropological concept that involves the building of a richly developed narrative that tells the story of another in a way that is faithful to cultural, historical, and contextual complexity (Carnevale, 2005). Ultimately, my purpose was to produce a storied account (Frank, 2004b) of the multiple realities at play (Appleton & King, 1997) involving how delirium relates to the facilitation of good deaths within hospice culture.

It is important to mention that analysis was not a solitary activity. Rather, I received regular input from my primary supervisor and thesis committee in interpreting the data throughout my fieldwork. My primary supervisor is both a palliative care nurse and a qualitative researcher with expertise in delirium. One thesis committee member is not a nurse (she is a medical anthropologist with expertise in ethnography and palliative care) and another's primary area is not palliative care (she

is a nurse and has expertise in qualitative research). Discussing my experiences of fieldwork with these research team members, who each come from different backgrounds, strengthened our potential to achieve a rigorous analysis (Russell & Gregory, 2003). Our work together meant considering the data from diverse perspectives and generating important questions that I could not have conceived alone.

Ethical Considerations

Ethical approval for this study was given from both the University of Ottawa Health Sciences and Science Research Ethics Board (Appendix B) as well as the research ethics committee of the study site. This hospice research ethics committee included representatives from the board of directors, senior management, as well as nursing, medical, and counseling staff.

In this section, I elaborate on some of the ethical considerations in designing and conducting this research project.

Vulnerability.

Given that this research involved a vulnerable population (i.e., severe and terminally ill patients, cognitively impaired patients, grieving family members), it is important to reflect on the unique ethical challenges inherent to this study.

Much of the discourse expressing concern over research participation in end-of-life contexts centers on balancing potential benefits from risks and harms, and argues that because of their dying, those close to the end of their lives have no potential to benefit from the results of research (Addington-Hall, 2002). Bruera (1994) suggests that the vulnerability of palliative care patients and their families stems from the “devastating physical and psychosocial symptoms” (p. 7) that are often characteristic of the end of life experience, and cautions that careful decisions need to be made about the types of research allowed in such settings. Dean and McClement (2002), writing about palliative care research from a nursing perspective, outline three dimensions of vulnerability, each of which they say applies to the palliative care population. Intrinsic vulnerability arises from personal factors such as increased age or reduced cognition. Extrinsic vulnerability has to do with one’s circumstances, such as hospitalization. Finally, relational vulnerability stems from interactions between people, for example dependence on caregivers. Addington-Hall believes that palliative care patients are

indeed vulnerable in that they are often fatigued or distressed and that there is a danger of coercion given their position as a captive audience.

For the reasons outlined above, any research undertaken in a hospice context needs to be extremely mindful of participant vulnerability. While respecting basic standards such as informed consent and confidentiality are absolutely necessary, they are not sufficient. Rather, my ethical engagement in this setting meant continuously questioning my place within the hospice and examining from multiple standpoints whether my presence or participation was in any way harmful or bothersome.

As will be described in the findings chapters of this thesis, hospice caregivers maintain a tight control over the hospice as a safe space for patients and their families. I am therefore confident that if my presence in the hospice was felt to be disturbing to any of the research participants (patients, families, or caregivers themselves) I would have been made aware of this. This did not occur. Rather, I regularly received positive feedback from hospice caregivers about my presence in the hospice. This seemed to relate to their own appreciation of my presence (e.g., enjoying our conversations) but also pointed to the fact that they were aware of and satisfied with the impact that my presence had on their patients. This was apparent when, for example, a nurse remarked to me (in front of her colleagues) that her patient had mentioned to her my earlier visit with him the previous day and that he had enjoyed it.

An automatic and blanket assumption of participant vulnerability for palliative care research, while serving the important function of protecting people from harm, requires a thoughtful analysis. Uncritical application of the vulnerability thesis is potentially limiting and restrictive and may paradoxically constrain the moral agency of those whose ethical interests it is designed to protect. Assuming that people in palliative care are intrinsically vulnerable because of their circumstance can result in paternalistic stances that deny dying patients and their families the opportunity to participate in research (Koenig, Back, & Crawley, 2003; Lee & Kristjanson, 2003). Evidence exists that presumed vulnerable populations are more resilient than they are given credit. For example, in conducting research interviews with recently bereaved family members, Seamark et al. (2000) found that of 79 cases, only one had to discontinue the interview due to severe distress, and 75 percent of participants found

the interview helpful. These participants stated that the interview was their “first chance to speak openly about the death,” it was “good to talk,” and it gave them “a chance to express anger and discuss issues regarding care” (p. 56). A similar picture emerged through the results of a study by Emanuel et al. (2004) where interviews with patients and caregivers involving questions about personal meaning of impending death and plans for terminal care were generally not perceived as stressful and in many cases were perceived to be helpful.

Qualitative research in EOLC carries the potential to generate important insights into the experiences and attributed meanings of people at the end-of-life and their families, which can empower us to improve care. Although this is important, it does not in itself negate the vulnerability argument from an ethical perspective. A case can also be made, however, for the use of qualitative methods as a mechanism for knowledge development that is *most commensurate* with the needs, values, and wishes of this unique patient and family population. The belief that all human research treats persons as a means to an end is overly absolutist (Dean & McClement, 2002). Consistent with Cicely Saunders’ philosophy that “you matter because you are you and you matter to the last moment of your life” (CHPCA nursing standards committee, 2009, p. 10), qualitative inquiry in palliative care can begin from the premise that dying people are living a story worth telling and learning from. As Mount (2003) has said,

...the path Saunders has set leads us to re-examine ancient questions that pertain to healing, wholeness and the true meaning of *health*. The dying have much to teach us in this regard if we have eyes to see and ears to hear. (p. 42, original emphasis)

The palliative care researcher who develops an approach based on adaptability and flexibility (Seymour et al., 2005) can tailor the methods of data collection to suit the available energy and resources of participants (Lee & Kristjanson, 2003). I consistently maintained an attitude of adaptability and flexibility regarding data collection throughout my fieldwork. For example, while I had received ethical approval to conduct audio-recorded interviews with patients and families, I decided very soon after entering the hospice that such an approach was not the best fit here. Patients were often very tired and I often found it more appropriate (and more interesting) to

chat with them for small moments at a time. Patients were able to engage in rich and meaningful dialogue during these short and spontaneous conversations that centered questions such as “How are you doing today?” and “What matters most to you right now?” I learned much from patients through these brief and unscheduled encounters and they seemed to appreciate my visits (e.g., by thanking me, inviting me back, or expressing happiness at seeing me again). Because my interest in patients’ perspectives was to provide context to my more specific focus on the provision of hospice care (i.e., this is not a study about the lived experience of being a hospice patient), I found that turning on my tape recorder for these conversations was unnecessary and not worth the potential burden that it might impose. Likewise, conversations with families were often spontaneous, happening while crossing in the hallway or for brief moments at the patient’s bedside. While I did sometimes interact with families in private locations within the hospice, these were generally meetings scheduled between family and hospice caregivers that I was subsequently invited to attend (i.e., these meetings would have happened anyway regardless of my presence). I did not schedule conversations (audio-recorded interviews) with family members as I felt there was a risk that such scheduling would be intrusive. When family members were present at the hospice, they were there to be with the patient, and time before death was often short. Again, as this was a study about the provision of hospice care and less about patient or family experience, I realized upon entering the field that collection of audio-recorded data from patients and families would provide very little ‘value-added’ and was therefore not worth the potential burden this might pose on their lived experience of the hospice space. Thus, the decision to not audio record interactions with patients and with families was made for both methodological and ethical reasons and resulted from following my own assessments about the most appropriate ways to navigate the emergent research design. In constructivist inquiry, the researcher is himself of herself the instrument of data production (Creswell, 2007). The researcher makes most fruitful use of this notion when he or she evidences responsiveness to contextual cues in moving the study forward (Appleton & King, 1997).

All of that said, I was pleasantly surprised by the eagerness and enthusiasm expressed by certain patients for the opportunity to engage and tell their stories.

Several patients provided positive feedback and confirmed their personal interest in the study as we discussed my project. One patient commented that he was excited to participate in something that may prove useful to others in the long term. Similarly, family members often seemed happy to engage with me over the course of fieldwork. For example, one morning I sat with the wife of a patient on a couch in a common living area just outside her (unconscious) husband's room at the far end of the hospice. Later in the morning, while I was sitting in the nursing station, this woman's daughter approached and asked me if I'd like to talk with her as well. She mentioned that it was "good" for her mother to talk and likewise was interested in sharing her own experience. We took a seat in a common area and had a conversation. Before we were done, this woman's brother-in-law (and son-in-law of the patient) approached us and asked "What about me? Can I talk to you too?"

Qualitative research such as the type I am reporting on here arguably offers potential for participants themselves to benefit. In reflecting on the dying experience during informal conversations with me, family participants were provided an opportunity to derive meaning from a sad situation and an opportunity to be heard (Dean & McClement, 2002). Throughout my fieldwork, I strove to invite research participants into a collaborative, non-hierarchical relationship, which is the approach most ethically suited to research with people who may be vulnerable because of their end-of-life circumstance (Seymour & Clark, 1998).

Not all patients and families, of course, were overtly enthusiastic about conversing with me. While no one ever expressed feeling upset or disturbed by my presence, I could sense that some patients and families had little interest in me and my purposes. I therefore took my cues from them in determining the nature of our relationship. Beyond making patients and families aware of who I was and what I was doing in the hospice, the decision about whether to further engage with me was entirely their own. Also, I generally avoided meeting patients and families within the first twenty-four hours of their admission. This was suggested to me by the hospice caregivers as a means of not burdening patients and families during an already overwhelming time. I agreed with this suggestion and further felt that it would help avoid confusion regarding my non-clinical role within the hospice.

Informed consent.

In all of my interactions within the hospice, I attempted to be explicitly clear about my role as a researcher. I wore a name tag during fieldwork that identified me as such. In all initial interactions with patients and with family members, I introduced myself as “the person doing a research project here.” When patients and families were curious to know more I provided further information.

The main focus of participant observation and the sole focus of formal interviews were hospice caregivers. Written informed consent was obtained from these hospice caregivers (see Appendix C). As I mentioned above in my discussions about the writing of fieldnotes, I worked toward an ethic of transparency concerning the nature of my involvement in the hospice as a researcher who was perpetually recording my observations and experiences. Further, I had open and honest conversations with hospice caregivers about my evolving impressions and preliminary analyses. This was an important element of enhancing credibility (see below), but was also useful in keeping hospice caregivers truly informed about the project in which they were participating. Our relationship was long (over a year) and therefore on several occasions I sought feedback as to their opinions about my involvement and presence in their daily work. Sometimes I was offered such feedback unsolicited. As I mentioned earlier, this feedback was always positive.

I also approached a select group of patients and families for participation in observation and informal interviews, although as I stated above, none of these interviews were audio-recorded. Patients and families with whom I interacted over an extended time (i.e., longer than a few minutes) and about whom I recorded detailed fieldnotes provided written informed consent (Appendixes D & E). Many more patients and families, however, were not the main focus of observation or informal interviews yet nevertheless informed my ongoing observation and analyses as I observed hospice caregivers in their work. Every effort was made to ensure that these patients and families understood who I was and my general purpose in the hospice space. Generally these introductions happened as I followed hospice caregivers on their rounds, going from room to room at the start of the nursing shift. In all other interactions, I sought and received permission from patients and families to be present. In all situations

where I or others judged that my presence might be unwelcome, I avoided any observation and interaction, e.g., with specific patients who because of paranoid delusions might be frightened by ‘strangers’ in their room, or with family members who were experiencing moments of acute grief.

In the findings chapters, when I present fieldnote excerpts that rely heavily on my having conversed with patients or families, these are people who provided written informed consent. Conversely, I sometimes describe an observation of a hospice caregiver where a patient or family member is accessory to this description (e.g., description of a nurse giving a family member a hug). In these cases, I have anonymized details of the encounter either by omitting or changing any patient or family information that might result in identification.

Trustworthiness

According to Morse et al (2002), “without rigor, research is worthless, becomes fiction, and loses its utility” (p. 2). These authors suggest that the integrity of a qualitative project ultimately depends on the responsiveness and analytic abilities of the investigator, who is faithful in attending to questions of rigour and trustworthiness at *all stages* of the research process. While notions of what constitute appropriate standards for judging the integrity of qualitative research have been hotly debated (Caelli, Ray, & Mill, 2003; Rolfe, 2006b), Carnevale (2002) suggests that because nursing is an interventionist discipline, some standard against which to judge the adequacy of individual qualitative studies is necessary. Drawing on concepts originally developed by Lincoln and Guba (1985), he suggests credibility, confirmability, saturation, and transferability as a set of four considerations which, together, represent a comprehensive approach to establishing trustworthiness in qualitative nursing research. In the sections that follow, I discuss the ways in which I considered each of these dimensions in designing and conducting my study. I do not however mean for this discussion to encourage a ‘checklist’ appraisal of the quality of my work. I agree with Morse et al that building integrity in qualitative research is a continuous process that depends on the overall responsiveness and analytic proficiency of the investigator:

Rather than relegating rigor to one section of a post hoc reflection on the finished work (such as stating that an audit trail was maintained, that member checks

were done, or that the researcher was “reflective”), verification and attention to rigor will be evident in the quality of the text. Excellent inquiry is stunning: the arguments are sophisticated in that they are complex yet elegant, focused yet profound, surprising yet obvious (p. 15).

Thus, the following discussion is meant to invite the reader to understand not only specific strategies that I employed to strengthen the integrity of my work, but also my overall understanding of what constitutes quality in qualitative research. It is through these ways that I endeavored to produce a rigorous, trustworthy, and ultimately meaningful final product for our discipline.

Credibility.

Credibility, which is the believability or “truth value” (Carnevale, 2002, p. 126) of the study findings, was fostered in this study through multiple modes of data collection (observation, interviews, and document analysis) as well as through a lengthy process of fieldwork during which authentic, reciprocal, and respectful relationships with research participants were cultivated.

Triangulation as a strategy to converge upon a single truth through the use of multiple methods betrays the paradigmatic foundations of constructivist inquiry. The use of multiple methods of data collection, however, remains a reasonable strategy to enhance the credibility of the study findings. This is not through pinpointing a single objective reality but rather through exploring different angles through which to view the research problem. By collecting data in different ways, parallel data sets are constructed with each providing a partial view of the whole picture, thus enriching the depth of interpretive possibility (Barbour, 2001). This approach is supported by the argument that triangulation enhances the completeness of the data (Atkinson et al., 2003). According to Tobin and Begley (2004), enhancing data completeness is commensurate with a constructivist perspective. They write that

Completeness is important to qualitative inquirers, as it allows for recognition of multiple realities. Inquirers are thus not using triangulation as a means of confirming existing data, but as a means of enlarging the landscape of their inquiry, offering a deeper and more comprehensive picture. (p. 393)

Development of authentic relationships with research participants is the second way by which credibility of the study findings is fostered. The quality of relationships

between researcher and participants in constructivist inquiry is determinant of the depth and richness of data that results. When there is no trust or rapport, the researcher can expect only to generate superficial data (Appleton & King, 1997).

Feminist philosophies of science have been particularly illuminating on the issue of relationship between researchers and participants (Campbell & Bunting, 1999; Campbell & Wasco, 2000; Ford-Gilboe & Campbell, 1996). Feminist methodology insists that egalitarian relationships create the intimate space required for mutual disclosure, reflection, and interpretation (Bloom, 1998; Sigsworth, 1995). Such a conception exposes the traditional role definitions of 'objective researcher' and 'passive subject' as androcentric and exploitative. Oakley (1998), for example, wrote about her experiences interviewing women about pregnancy. She found conventional norms for qualitative interviewing problematic, such as the requirement to deflect participant questions not related to the research question. She argued that such a positioning vis-à-vis study participants constitutes a barrier to the fostering of reciprocity, required if knowledge of an intimate and personal nature is to emerge. I agree with Oakley and suggest that it is neither possible nor desirable for a qualitative nurse researcher to suspend her/his identity as a person while conducting data collection, particularly in a field where knowledge of such intimate experiences as death and dying are under exploration.

Across qualitative research traditions is an envisioning of the researcher-participant relationship as an active site of interaction between people that fosters the co-construction of meaning (Cutcliffe & McKenna, 2002; Finlay, 2002; Mills, Bonner, & Francis, 2006). An approach to data collection that emphasizes detachment and objectivity is therefore pernicious to the development of a reciprocal relationship, which is necessary for gaining authentic access to the lived world of the other. The negotiation of trusting relationships with research participants was a complex process that involved striving for "cultural acceptability" (Mulhall, 2003, p.310) within the research setting. This was achieved through continuous thoughtful reflection about how to present myself (e.g., dress, language, and behaviour) and also careful navigation of the insider-outsider dialectic (Allen, 2004) referred to earlier. For example, I believe that being a palliative care nurse elsewhere facilitated the gaining of hospice caregiver

participants' trust in this setting. This was not because of an automatic appreciation of my status, but rather because we spoke a common language. Nurses and other caregivers here engaged me in conversations that probed my values, and it quickly became clear that many of the things that are important to them (e.g., the end-of-life wellbeing of their patients and their families) are things that matter to me as well.

Authentic relationships with hospice caregiver participants in this study enabled a mutual and collaborative inquiry in which ongoing hypotheses and interpretations were shared and deepened through dialogue (Baumbusch, 2011). Throughout the study process I offered study participants emerging interpretations and solicited their feedback on these. Toward the completion of fieldwork, I gave two formal presentations at the hospice that summarized and invited discussion about the results of my data analysis and outlined a preliminary structure for the findings chapters of this thesis. Consistent with a constructivist approach to inquiry, these practices were not employed as member-checks, aiming to pinpoint and verify a correct interpretation of reality. Indeed, member checking is problematic as a quality standard for qualitative research; it risks constraining the analytic potential of the research by encouraging the researcher to *report* rather than to *interpret* data from the field (Morse et al., 2002). My interactions with participants just described were more akin to what Tracy (2010) calls member reflections. This practice is not about returning to participants to identify a "single truth", but rather strives to create a "space for additional data, reflection, and complexity" (p. 848).

Confirmability.

In a reflection on philosophy of science from seventeenth century England, Shapin (1998) distinguishes between the public space of the laboratory and the private space of the alchemist's closet, explaining that in these times the experimental foundations of knowledge had to be attested to by eyewitnesses. He writes that "the reader was to be shown not just the products of experiments but their mode of construction and the contingencies affecting their performance as if he were present" (p. 115). This example has relevance to contemporary questions of integrity in qualitative research: how are we to trust that research findings are not merely fictitious inventions by the researcher that bear little semblance to the lived realities of

research participants? According to Carnevale (2002), confirmability of study findings is supported through an audit trail, which refers to “the maintenance of detailed records of the data-collection and analysis process, whereby a reader could confirm that they would arrive at the same conclusions” (p. 126). Such a criterion for confirmability is problematic for the type of constructivist inquiry described in this thesis. Interpretation of study findings is necessarily a personal process, where the thoughts, feelings, and analytic orientation of the researcher inevitably shapes the interpretive process. Individuality of interpretation is not inherently problematic, and can actually pave the way toward deeper understanding. For example, Drew (1989) has described how her emotional reactions to study participants during phenomenological inquiry led to the creation of new categories for data analysis. Findings in qualitative research are co-constructed through the researcher-participant relationship; they do not stand outside of the research encounter and thus are not necessarily reproducible by a different researcher, all other things being equal. Nevertheless, the idea of an audit trail that records the methodological process of the researcher is important, so that readers of the research report can judge for themselves the plausibility of the unique interpretations that are offered (Koch & Harrington, 1998). The key concept here is researcher reflexivity, where rigour of qualitative research is upheld when researchers adequately describe and explicitly interpret their experience-as-researcher. Koch (2006[1994]) provides a model example of researcher reflexivity, whereby in providing detailed excerpts from her field diary, she shares with readers the various decisions she took as a researcher throughout her study, her experiences of moral distress as she observed care practices that she believed to be substandard, and her reflections on the inevitable role fusion that occurred between her identity as a nurse and her identity as a researcher. The main point is that within a paradigm that acknowledges knowledge as constructed through interaction, deliberate reflection about *how* such knowledge is produced contributes to the overall integrity and authenticity of the final product. This process of reflexive journaling contributes to the overall authenticity of the study, whereby the inevitable influence of the researcher on the research setting and interpretation of study results is explicitly taken into account (Koch, 2006 [1994]; Rolfe, 2006b). Confirmability in this study was facilitated

through the writing of reflexive memos within fieldnotes, the contents of which constituted a primary focus for data analysis.

Saturation.

Saturation refers to the idea that an adequacy of depth has been reached, in which addition of more data or further analysis does not contribute to the overall value of the study (Carnevale, 2002). The meaning of saturation as a methodological concept was originally specific to grounded theory. In that context, *theoretical saturation* is attained when analytic categories have been sufficiently developed and relationships between them thoroughly explained such that new theory can emerge (O'Reilly & Parker, in press). The idea of data or thematic saturation however, supposedly attained once nothing 'new' is emerging in the analysis, now dominates as a generic hallmark of rigour across qualitative research approaches (O'Reilly & Parker, in press). This is problematic however for a constructivist epistemology that acknowledges the potentially limitless interpretations that are possible in a qualitative project. Therefore it is important to be clear that in this study, saturation refers only to the process by which I came to decide that data collection could cease. This involved judgements about whether my own interpretations had evolved to a point of sufficient depth and complexity such that a genuinely holistic account could be written. Saturation then is a form of *narrative integrity*. Through the circular processes of data collection and analysis, analytic activities evolved from coding and memo writing into chapter writing and storytelling. Toward the end of fieldwork, visits to the hospice ceased to yield meaningful insights relevant to this process of ethnographic writing. This supported the eventual decision, after many months of fieldwork, that it was appropriate to leave the field.

Transferability.

Ethnographic description is the cultural analysis of one particular group with the goal of generating knowledge transferable to other situations (Flaming, 2001a). Transferability refers to the "extent to which the findings 'fit' with the experiences of persons in similar contexts" (Carnevale, 2002, p. 126). The setting chosen for this study is a highly specialized care context and is not typical of the multitude of environments where people receive EOLC. Nevertheless, the focus of analysis in this study is the

fostering of a good death for those with delirium through attention to notions of dignity and relationship; these are theoretical constructs that are broadly relevant across settings. While findings generated from constructivist research are necessarily context-bound, the insights such findings generate can (and should) resonate with others. Resonance is the “research’s ability to reverberate and affect an audience” (Tracy, 2010, p. 844). Presented with a description and analysis of the daily realities, practices, and relationships internal to this hospice community, readers will consider the ways in which my interpretations overlap with their own particular situations or purposes. The point is not for the “fit” to be perfect. Indeed, it is in reading about cultures that are different from our own, in subtle or radical ways, which makes ethnography relevant to our own lives. Ultimately, the insights generated through this research will have *theoretical currency* for a multitude of contexts. Broadly, such contexts potentially include end-of-life care, care of patients with delirium and other cognitive impairments, and also any other context in which the caregiving relationship between provider and recipient shapes the moral experience of health and illness.

Summary of Methodological Considerations

In this chapter, I have outlined ethnography as the methodology of choice to answer the question: *What is the relationship between end-of-life delirium and the good death in hospice care?* I described my motivations for designing a participant-observation study of nursing practice and my relativist ontological and constructivist epistemological orientations. I further suggested that such an approach to research is consistent with a theoretical framework grounded in human relatedness and palliative care as a discipline concerned with understanding the experiences and meanings of health phenomena *as lived* for patient, families, and end-of-life caregivers. I briefly introduced the reader to some of the specifics of the setting for this study as a freestanding residential palliative care setting, a hospice. More information about the context of this hospice, however, will be provided in the next chapter, as we now move into the findings and I take the reader into the hospice space.

We are here.

We will be with you in your living
and your dying.

We will free you from pain and give
you the freedom to find your own
meaning in your life
your way

We will comfort you
and those you love
not always with words, often with
a touch or a glance

We will bring you hope
not for tomorrow
but for this day

We will not leave you
we will watch with you
we will be there

Figure 3. "We are here." Poem displayed on the wall of every patient room in the hospice.

I would like to once again tell you how thankful I am for the warm and tender care you gave to my husband during his stay. He so benefited from your care, that he left us with serenity, and the end of his life was filled with love and with peace.

Figure 4. From the wife of a hospice patient. Posted on a wall in the nursing station

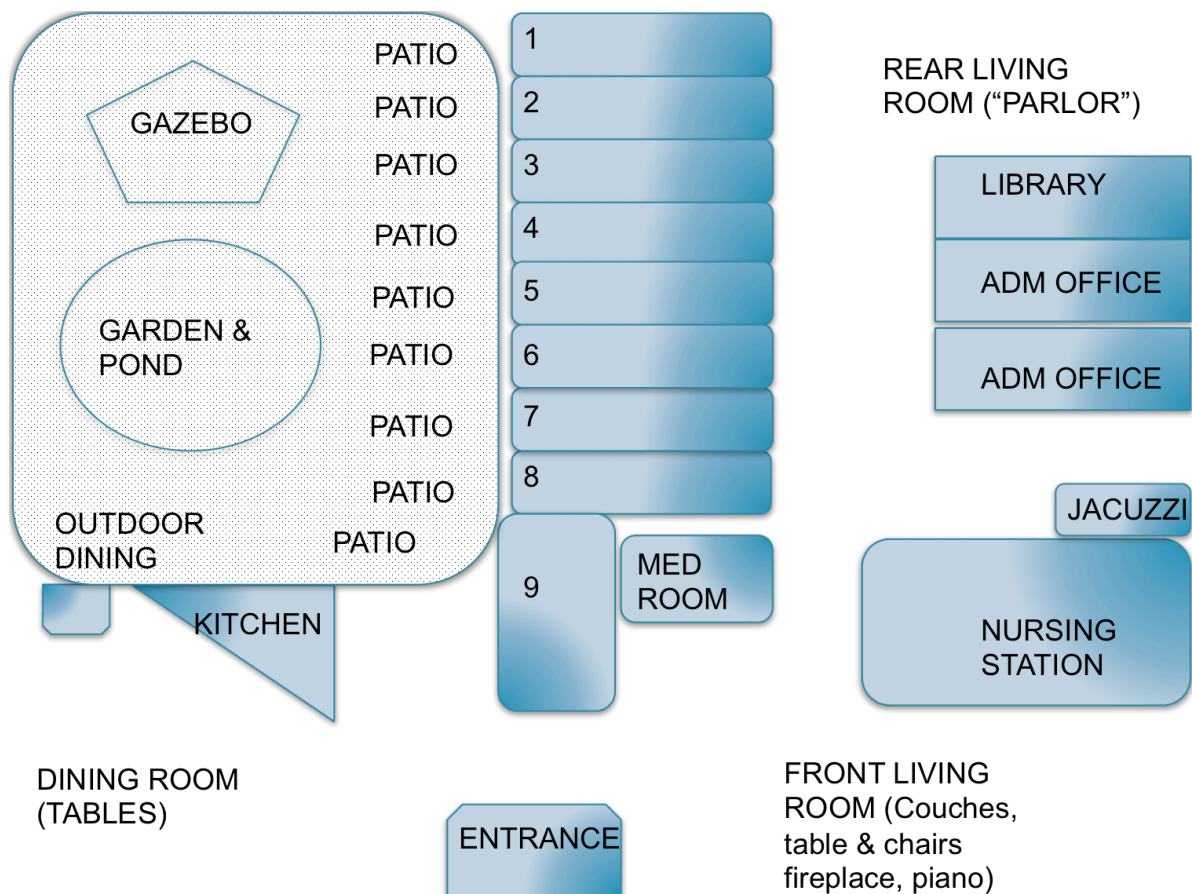


Figure 5. Map of the hospice space (Numbers 1-9 refer to patient rooms. 'ADM OFFICE' refers to the offices of the Executive Director and the Assistant Executive Director - Nursing).

Chapter 4: Creating a Place for a Good Death

Introduction

This chapter introduces the reader to the specifics of the hospice as a place where the idea of the good death is put into practice. The chapter is organized into three sections. First, I introduce the various people within the hospice space (patients, families, and caregivers) and describe some features of its architectural layout. Second, I invite the reader to experience a day in the life of hospice caregiving, chronicling the daily activities of the hospice caregivers, particularly the hospice nurses. Finally, I describe some of the values and beliefs that hospice caregivers share, and provide some analyses of how this shared value system influences the provision of care and shapes the relationships developed with patients and their families. This chapter begins to respond to the first research objective: *Articulate an emic perspective of hospice caregiving culture to interpret the practice of nurses and other caregivers in their facilitation of good deaths for terminally ill patients and their families.* Together, analysis of the cultural features of hospice caregiving, i.e., the people, the space, the practices, the prevailing values and beliefs, generates an understanding of the central ethos here: creating a safe place for good deaths to occur.

People and the Spaces they Occupy

Many members of the hospice community believe that the ideal death is the death that occurs at home. One hospice caregiver referred to the hospice as the “plan B” for those who are not able to achieve a home death. It seems fitting, therefore, that the architecture and furnishing of the hospice imitate a homelike environment. Further, many hospice caregivers refer to the hospice as a “house.” This house has multiple living spaces with tables and chairs, sofas, fireplace, bookshelves, television, and a computer. On sunny days light streams into these living spaces through large floor-to-ceiling windows and illuminates the various pieces of artwork and tapestries hanging. In the kitchen and dining area meals are prepared and staff, families, and patients gather around the few tables that comprise the dining room and outdoor patios. In the evening, the soft lighting and beige painted walls create an orange glow throughout the hospice that is warm and inviting.

The nine patient rooms are large and each is furnished to resemble a personal

bedroom. There is ample space around the bed for people to gather and move about. Each room opens, through large glass sliding doors, onto a private back patio with lawn chairs and tables. These patios open to the common backyard, which contains many trees, a garden, a rock pond, and a gazebo.

There are three groups of people who constitute the hospice as a living community. First, there are the patients. They have all been diagnosed with a life-limiting illness, and are expected to die very soon. An expected lifespan of three remaining months or less qualifies a patient for admission here. Most of the patients have end-stage cancer, though some have other terminal diagnoses such as amyotrophic lateral sclerosis, heart failure, renal failure, and pulmonary fibrosis. Many of the patients have undergone months or years of treatment directed at curing or stabilizing their underlying illness. Many look very sick; they are weak, tired, and unable to perform activities of daily living, such as walking, dressing, bathing, or eating without assistance. These patients often have difficulty talking, thinking, staying awake, and even breathing. Other patients however, although just as ill from a life-expectancy perspective, do not look as sick; they are alert, energetic, and mobile. They are able to enjoy many of life's pleasures such as good food and good company. If wearing their own clothes, these patients are sometimes indistinguishable from visiting family members by appearance alone.

Next, there are the family members. Most of the patients have family present during their time in hospice. Family in this setting refers to anyone who presents to the hospice with a vested interest in the patient's wellbeing. Family is not limited to individuals related to the patient through biology or marriage. Family members are warmly welcomed into the hospice and are encouraged to make use of the space in whatever way is most helpful to them. Much of the architectural features that contribute to an overall homey atmosphere, e.g., large and well-decorated living and dining areas, are for the benefit of family. There is ample room for family to gather or to be alone. Sometimes family members appear to be in good spirits, smiling and laughing, while at other times they appear nervous, exhausted, or upset.

Finally, there are the hospice caregivers. These are the people who have made a professional or volunteer commitment to show up and perform some function toward

achieving the overall goal of the hospice, which is to provide an environment of peace, comfort, rest, and support for the dying and their families. Hospice caregivers include paid staff workers: nurses and nursing assistants, physicians, patient care attendants (i.e., unlicensed care aides), a psychologist, and a social worker. Hospice caregivers also include many volunteers, including the music therapist and the pastoral care provider. Some volunteers assist with direct patient care, while others work in reception, in the kitchen, and in maintenance and housekeeping. The patient care volunteers:

Support both the families and the patient both emotionally and physically with any small tasks that are needed -*Volunteer*

This includes helping patients with meals and showing family around the hospice on admission. The patient care volunteers also assist with some of the nursing care, e.g., bathing and transferring, in the presence of a nurse.

The hospice is a space where the lives of all of these people, patients, families, and hospice caregivers, intersect. Everyone interacts with everyone else, usually addressing each other by first name. Patients are also referred to by first name, even in some of the formal systems of operation such as nursing documentation and during team meetings.

The hospice is divided into different areas (see figure 5). Because patients are often fatigued and have limited mobility, they generally spend most if not all of their time in their own rooms. Nurses and other caregivers interact with patients and family members here, but otherwise the rooms are a private space. Doors are often closed and signs are sometimes posted alerting passers by to keep noise to a minimum. Common areas are accessible to everyone and are often the location of interactions between caregivers and care recipients, particularly families, or between care recipients themselves, e.g., family members of different patients coming together in these spaces. These public areas are also sometimes made private. For example, caregivers will meet with family members in the library and close the door.

In her ethnography of an interdisciplinary geriatric oncology team, Ellingson (2003) draws on the work of Goffman (1959) to illustrate the negotiation of frontstage and backstage spaces within the care environment. She writes that, "Expressing emotions in the backstage (away from patients) assisted team members in controlling

their emotional display while in the clinic frontstage, thus preventing team members from disrupting the team's performance of calm professionalism" (Ellingson, 2003, p. 102). As the following excerpt from an interview with a nursing leader shows, a similar frontstage / backstage division operates in this setting. There are several areas available in the hospice for caregivers to interact out-of-sight and out-of-earshot from patients and family members. Team rounds are held once a week. In this hour-long meeting, hospice caregivers gather in the upstairs conference room (not shown on map) and discuss all of the patients who died that week as well as all of the patients currently at the hospice. Other areas in which out-of-sight and out-of-earshot interactions occur include the medication room and the nursing station. Hospice caregivers make use of this backstage space to work through their own understandings and reactions to patient and family situations, so that they can then be optimally supportive in their frontstage interactions.

The times that we have difficulties understanding why families are choosing certain options, or patients certain options, that's discussed in rounds. So there's a forum to get out that frustration, away from families as opposed to in front of the families. It's a safe place to say, wow, I don't understand why the family is letting the patient suffer, and why we can't give more medications. Like that would be a prime example. So that's discussed away from, and then it's worked through as a team. So when people have problems, we discuss them together so that support can be given. –*Nursing leader*

A Day in the Life of Hospice Caregiving

There are three eight-hour nursing shifts at the hospice: the day shift from 7:30 am to 3:30 pm, the evening shift from 3:30 pm to 11:30 pm, and the night shift from 11:30 pm to 7:30 am. Typical staffing is as follows: two registered nurses and one nursing assistant during the day shift; one registered nurse, one nursing assistant, and one patient care attendant during the evening shift; and one registered nurse and one nursing assistant during the night shift. Throughout this thesis, when I generically refer to "nurses" I am referring to both registered nurses and nursing assistants. This is because, while the scope of practice of registered nurses and nursing assistants as legally defined by their respective professional orders are different, I found their practice to be virtually indistinguishable in this hospice. Nursing assistants here take a full patient assignment and implement all of the nursing care in the same ways that

registered nurses do. Patients and families here know these caregivers as “nurses,” and do not differentiate between registered nurses and nursing assistants. The patient care attendants, meanwhile, do not take a particular assignment, but rather assist all of the patients with activities of daily living, e.g., hygiene and mobilization. Unlike the nursing staff, patient care attendants are not regulated by a professional order.

Sometime between 7:15 and 7:30 am, the nurses for the day shift arrive. As they wait for each other to be ready for change of shift report, they chat socially. They also discuss amongst themselves patients who may have died since the last time they worked. These chats, which I came to think of as informal bereavement rounds, seemed to help nurses who were absent at the time of death achieve closure regarding patients they cared for. They discuss how the death went, whether it was peaceful, and how the family reacted. Sometimes, nurses coming on shift express amazement and disbelief at discovering that a particular patient they assumed would have died by now is still alive.

By 7:45am, change of shift report begins. The door to the nursing station is closed and the five nurses, 2 night shift and 3 day shift, sit around the large square desk in the nursing station, together reviewing all of the patients. Pertinent details of the previous shift are recounted, such as how many breakthrough doses of medication a patient may have been given, e.g., for pain, shortness of breath, anxiety, restlessness, and what the outcome of this was. Nurses describe the extent to which patients are “changing,” which signals that the patient is getting closer to death. Details of interactions with family members are also discussed. The nurses offer their interpretations of how the family is coping with the current situation: feelings they have expressed, as well as apparent reactions to the changes witnessed and to the care being delivered. If there is a patient expected to arrive later in the day and the information is available, the night nurse will transmit this information to the day shift, i.e., the patient’s name, gender, age, diagnosis, family details, circumstances of the current health situation, treatments recently received or withdrawn, current symptom issues. If a patient has died and the body is still here, information about whether the family is expected to return and any outstanding arrangements to be made with the funeral home are mentioned.

Once the night nurses leave, the day nurses negotiate the distribution of patients

amongst themselves. Each nurse takes her assignment for the day (i.e., responsibility for three patients), with attention paid to evenly distributing the workload. This means balancing patients with high care needs, incoming admissions, and follow-up care for deceased patients. Such follow-up care includes preparing the body for the funeral home and providing support to family members still present in the hospice. Nurses might opt to care for patients they “know,” having been assigned to them previously. Once the day’s assignment is established, the nurses start to read the charts of their select patients. As they read, they speak to each other about their plan for the day, e.g., “I’ll see if I can give her a shower today,” “I see his meds were changed.”

Sometime around 8 am the three nurses go on their “first round.” They walk together along the corridor to the far end of the hospice. Starting at room 1, they work their way back toward the front where room 9 is located. They go into every room as a group. If patients are asleep, they are not purposefully woken. Syringe drivers, i.e., devices that provide a continuous delivery of medication under the skin, are checked to ensure that they are infusing properly. If patients are awake, or if patients are unconscious, the nurses will speak to them. They introduce themselves by first name and as “the nurses for the day shift.” Short conversations between the nurses, patients and family members take place during this time. Quick assessments are made, e.g., *How did you sleep? Are you comfortable right now?* If the patient complains of discomfort and requests a breakthrough dose of medication, the nurse assigned to that patient will bring it once the round is complete. In the following excerpt, a nurse describes the focus of rounding as determining the overall comfort of the patient, and the urgency of response required when patients are uncomfortable.

When we go into the room first thing in the morning, we check their facial expressions and see how relaxed they look. If they have any furrowed brow, they’re moaning, things like that, or any agitation in their body at all. Generally that’s a good sign [looking relaxed] that you can tell that somebody’s comfortable. Whatever we’re doing, we’re doing something correct. And um, if we notice anything at all, of course we pounce on it right away and try to get the issue resolved. –*Registered nurse*

The entire round takes approximately fifteen minutes. Once completed, nurses return to their charts, attend to patients with immediate needs, or enter the medication room

to begin preparing morning medications.

After the morning round, one of the nurses will narrate an audio recording for that day's volunteers. There are three patient care volunteer shifts: 9 am to 1 pm, 1 pm to 5 pm, and 5 pm to 9 pm. The recording consists of a very brief summary of the information needed for the volunteers to work safely and effectively with the patients. This means providing details about such things as each patient's dietary status, i.e., whether they are eating and how much assistance is required, and mobility function, i.e., whether they can get out of bed and how much assistance is required. Volunteers throughout the day will listen to this recording at the start of their shift. At 9am, the first patient care volunteer for the morning arrives. She introduces herself to the nurses and then visits all of the patients to take their orders for breakfast. She takes these orders to the kitchen and when the meal is ready she delivers it to the patient.

After medications and breakfast, the nurses will start "care" for each patient. This means help with toileting, washing, and dressing. When patients are able and willing, nurses will bathe patients in the shower or Jacuzzi bathtub. When patients are unconscious and/or imminently dying, they are bathed in bed. The hygiene care provided is thorough: patients are washed, men are shaved, hair is brushed, moisturizing lotion and protective skin creams are applied, and bed linens are changed. As the following excerpt from my fieldnotes shows, hospice caregivers adapt their routines and the pacing of their care in response to needs arising from individual patients at various moments during the shift.

After this morning's first round, the nurses prepare medications in the medication room, and then help set the patients up for breakfast. On my offer if I can help with anything, one nurse, as she's hurriedly walking down the hall, asks if I can go into #8 because he's "climbing out of bed." She asks if I can "just tell him that the nurse will be with him shortly." I go in and he is lying sideways in the bed. He tells me that he wants to get washed and have a shave. He is very concerned that he will not be ready for when his visitors arrive. He says he just needs help to get to the bathroom and he can do it himself. I tell him that the nurse will be in shortly and he gets very frustrated, saying that he's not a demanding person and he knows the nurses have other patients but he really doesn't want to wait. I tell him that I will go and tell the nurses that he is waiting. I leave and approach the nurse in the medication room to confirm that she is on her way. She asks me, "Does he still have his legs through the side rails?" He did not. I return to the patient's room and we chat a little about the pictures on his

wall, painted by his grandchildren, and the photographs on his nightstand of his daughters. Within two minutes, the nurses arrive. We help him into a chair. This is somewhat difficult. He is very dependent and cannot stand on his own. While the nurses set him up for breakfast I change his bed linens, which are soiled with urine. One of the nurses takes his breakfast order: eggs, toast, coffee, and within a few more minutes the volunteer brings this to him and helps him to organize his plate. -*Fieldnotes*

At some point between 8 am and 10 am the physician arrives (Monday to Friday, and variably on weekends). The start to the physician's day is the "morning report." The physician sits with all the nurses, and sometimes also the psychologist and social worker when they are present, at the square table in the nursing station. The door to the nursing station is again closed, and each of the patients is discussed in detail. The nurse will relay information about the patient as gathered from the previous change of shift report, the chart, and whatever assessments she has made so far this morning. The following fieldnotes, taken during a morning report with the physician, reflect the typical format and content of these discussions.

Mrs. B is described by the nurse as experiencing: "restless sleep," dreams, always traveling, "trapped."

MD: Nightmares?

Nurse: No, apparently not. It's like she can't get to where she's going.

MD: Frustrated?

Nurse: It's vague for me. Does not seem to be disturbing to her.

The nurse mentions the patient's past hallucination of seeing Japanese people in her room and says "I would not feel good seeing Japanese people."

Someone asks: Why?

Nurse: "Because for me that symbolizes war, not calm."

The group discusses her PO (by mouth) medications, her ability to swallow, and her blood sugar levels.

The patient is described as becoming "weaker and weaker."

Mr. T is described by the nurse as: "actively dying" today. Big change. He became mottled yesterday and today. He is still in a lot of pain. He has a syringe driver with hydromorphone and midazolam. The nurses have been pre-medicating [meaning they administer analgesia in anticipation of painful experiences such as movement]. When you touch him he has pain. He's basically unresponsive except when he says "Ow!"

MD: He's actively dying?

Yes.

MD: And he's not dying well because he's in pain?

Exactly.

MD will increase the dose of the syringe driver and breakthroughs. -*Fieldnotes*

After report with the nurses, the physician visits each of the patients. The physician also meets with family members, sometimes outside of the patient's room. She writes a note in the patient's chart after that day's visit and will often make adjustments to the medications that the patient is receiving. The physician visits each patient once per day, though sometimes more depending on the circumstances of the patient's situation.

On any given weekday, patients and families can expect to interact with the nurses, volunteers, the patient care attendant, the physician, and the psychologist or the social worker (these last two caregivers are usually in the hospice on alternate days). Other visitors may include the pastoral care provider and the music therapist, both volunteers. Two senior managers, both health care providers by training, have their offices on the first floor and they keep their doors open throughout the day. This facilitates communication with families who wish to speak with them. These managers are also active participants in team discussions about individual patients. Weekends are quieter, with fewer people around. On the weekend there is no psychologist, social worker, or managers. Physicians may or may not be present, again depending on the particular needs of the patients staying at the hospice at that point in time. The nurse staffing on the weekend is the same as during the week. Further, other people who work at the hospice will also sometimes interact with patients and families. For example, one afternoon I was surprised and impressed to see a woman who works in the kitchen walking her dog down the hospice corridor. She had brought in her dog because she knew that a particular patient loved dogs. Overall, there is a strong sense of community whereby all members working at the hospice, regardless of role, are explicit in orienting their work toward the wellbeing of patients and families.

Every patient room is equipped with a call bell, which when pushed rings in the nursing station. Patients are also given a portable bell to ring if they are away from their bed and would like to call a nurse. Hospice caregivers answer the bells throughout the shift and attend to their patients' needs. Nurses help patients with

various tasks, such as being pulled up in bed or being helped into a chair to spend some time on the back patio. Nurses are also medicating patients for various “breakthrough” symptoms, such as pain, nausea, anxiety, shortness of breath, manifestations of delirium.

Throughout the day, hospice caregivers visit with patients and/or families, either alone or together with colleagues, and return to the nursing station to discuss and to document about these interactions. Details of these encounters, discussed in the medication room and nursing station, are elaborate. Hospice caregivers relay what was said, the emotions involved, and how people responded. Through their encounters with patients and families, hospice caregivers come to understand the major issues for each case and focus their caregiving attention around these.

At 3 pm, a “tea trolley” is prepared in the kitchen and is rolled through the hospice by a volunteer. Patients and families are offered tea, iced in the summer, and a variety of baked goods such as cookies and cakes that have been prepared in the kitchen. After the trolley has made its way through the hospice, it is left in the front living area near the nursing station where anyone, including hospice caregivers, can serve themselves.

Between 3:00 pm and 3:30pm, the two nurses and patient care attendant for the evening shift will arrive. The activities of change of shift repeat in much the same way as for the start of the day shift. The following fieldnote excerpt describes a typical start to an evening shift:

At 3:15pm, the nursing station starts to become crowded. Nurses from the day shift enter and finish their charting, and the evening staff begins to arrive. Today, the MD is seated in her ‘spot’ at one corner of the nursing station, the nursing team leader is seated at her desk in another corner, and the social worker stands in the third corner. People are offering each other their chairs to sit down, until one of the nursing assistants retrieves an extra chair from the living room just outside the door. The nursing station, quiet and nearly empty minutes earlier, is now buzzing with activity. Pockets of conversation are discernible, with people either chitchatting socially or discussing particular patients and family members. Everyone seems to be in a good mood. A little past 3:30 pm, one of the evening nurses asks if “they already counted?” referring to whether the day shift has already counted the narcotics, an activity that must be performed at the change of every shift. They have not. The team leader offers that she can count with someone, but the two evening shift nurses decide to

count together, as the day shift at this point does not seem ready to give report. The report begins at approximately 3:40 pm. Every nurse systematically goes through each of her patients, passing on to the next shift information that she deems relevant. In today's report, we hear descriptions of pain, i.e., who had pain, where the pain was located, whether it is new, and what was done / is going to be done to address it. We also hear descriptions of skin integrity ("her coccyx is red"), appetite, and elimination, i.e., whether a patient urinated, whether a patient had a bowel movement, and if not how many days it has been since they have. We hear about dressings that were done, medications that were adjusted, and patients who are described as "oriented," "pleasant," "in good spirits," or "agitated." The agitated patient is described as "becoming flustered when you disturb him," to which others nod their heads and voice their agreement. Methotrimeprazine (a sedating anti-psychotic) was given, and he seems more relaxed when family is present. We hear that family members of one of the patients have decorated the room to make it more "homey," to which others respond with enthusiasm: "That's nice!" One patient has just died, twenty-five minutes before the change of shift. The gown still needs to be changed and the Foley catheter removed. Another patient is "changing," and the nursing assistant giving this report describes having suggested the use of "a commode for next time" as well as insertion of a Foley catheter. The nurse does not say anything more, but it is understood that these suggestions are made in light of an expected progressive deterioration in functional ability that will make getting out of bed to go to the bathroom increasingly difficult and eventually impossible. Yet another patient is "dying" and was given midazolam (generally given here as a sedative, co-analgesic, and/or muscle relaxant), because she was "really moaning."

When the report is finished, the evening nurses divide the patients amongst themselves. The day nurses either leave or finish charting. As the two evening nurses discuss who will take care of which patients, they commit to ensuring that the assignment is evenly balanced with respect to workload. The patient care attendant gives her input on which patients are "light" or "easy," and which are more "heavy." As an example of this negotiation, today one of the patients is described as "agitated in the morning, but not so much in the evening," to which another disagrees: "Oh yes! It starts again in the evening" and that yesterday he "was a handful."

Once the evening nurses have their assignment for the shift, they begin their "first round" together with the patient care attendant. It is now 4pm. On this round, everyone enters every room together to greet the patients and any family members that are present. Syringe drivers are checked and assessments are made as to whether patients are comfortable or not. If patients are sleeping they are not woken. On several of the patient doors there are signs alerting potential visitors that the patient is resting, such as "sleep zone." This evening, there are many family members in the hallway just outside one of the rooms in which a patient has just died. One of the nurses introduces herself to these family

members. She has not met them before, the patient was here for a total of twenty-four hours. She tells them to advise her if they need anything. In other rooms, many family members are gathered visiting with patients and the nurses say a quick hello and then leave the families to their visits. In another room, a patient is awake, in bed, and is being visited by his sister. He is very jovial and makes jokes with the nurses, who spend about five minutes standing around the bedside, chatting and laughing with him. *-Fieldnotes*

The physician, social worker, psychologist, and managers finish their day and leave sometime after the evening shift has begun, and the nurses spend the first few hours administering prescribed medications and responding to patient needs as they arise. This is also a time of day when nurses interact extensively with families, who often visit during the late afternoon and early evening. At suppertime, the nurses and patient care attendant eat together in the dining room or outside on the patio if the weather is nice¹. When they have finished supper (usually by 7pm), the evening staff organizes “care” for the patients, which is basically a repeat of the morning care. They decide in which order to visit the patients, which patients the patient care attendant or nurse can care for on her own and which will require two people, e.g., for bathing, turning, and toileting. The kitchen staff and volunteers leave around 6 pm, and the last of the volunteers (receptionist and patient care) finish at 9 pm. At 11:30 pm the night nurses arrive and receive report from the evening shift. The following notes, taken during the evening-to-night report from one nurse to the others, are typical of the types of discussions that occur at this time.

Report for Mr. B in room #5:

Nurse: I’ve been in there a lot tonight with the family. They’re very anxious – I don’t blame them. They asked me many, many times, “When?” (i.e., when will he die). He became very congested tonight. Respiratory rate was 8 when I started. Shallow shallow. Colour is horrible. Feet are cold, hands warm. Coughing, choking, moaning. I medicated whenever he was moaning, obviously. The MD increased the breakthrough over the phone but I didn’t have to give it since. Lots of family support. I think he’s on his way out. The family keeps asking if they

¹ The lunch and supper break is about an hour. On both day and evening shifts the staff generally eats together. If a patient requires assistance from his or her nurse during this time, the patient care volunteer will come and tell this to the nurse who will interrupt her meal to see the patient. On evenings the patient care attendant has a pager that is connected to the call bell system. None of the hospice caregivers are ‘off’ during their shift. They are responsible for their patients during their break, and do not leave the hospice premises during this time.

should call their sister, but he could go any second or this could go on. *-Fieldnotes*

Overnight, the only people in the hospice are the nine (or less) patients, any family members that are staying the night, and two nurses. One cot and bed linens are made available in each patient room for a family member to sleep. The hallway and common areas are dark and empty. The two nurses spend most of the shift in the nursing station, checking in on every patient every one to two hours, and responding to the call bell whenever it rings. They also perform other tasks such as checking the medical orders for all of the patients, and preparing a new dossier for the patient(s) that will be admitted the next day. Each will spend her break sleeping for about 90 minutes during the shift. Sometime between 6:45 am and 7:00 am, the two night nurses perform their final round of all the patients. Some of the patients are woken to be turned, positioned, or pulled up in bed. Patients who wear diapers (incontinence briefs) are also checked at this time for incontinence, and cleaned if needed.

In describing the daily practice activities of hospice caregivers over the course of a twenty-four hour day, two regular events merit specific attention: patient admissions and patient deaths. Patients are generally admitted to the hospice Monday through Friday, between 10 am and 3 pm. The hospice accepts admissions at these times because this is when a physician is present to perform an initial medical assessment and prescribe medications and treatments. Many patients are admitted from a general hospital that is adjacent, though not affiliated, to the hospice. In fact, when hospice caregivers feel that a patient coming from this hospital needs to be admitted as soon as possible because of current distress and need for palliative care, they will sometimes go to the hospital themselves and wheel the patient via stretcher through the parking lot that connects these two buildings. Other patients are admitted from home, from long term care settings, or from other hospitals. On admission, the patient is helped into the bed or a chair. The nurse meets with the patient and the family, and ensures that the patient is comfortable. The following reflection of a nurse having admitted a restless patient the previous day shows the approach to assessment and intervention in a newly admitted and apparently uncomfortable patient.

The gentleman who came in yesterday...I was thinking pain.

David: Right.

When I saw him with movement.

David: This is in number one right?

Yeah. I saw him with movement and he was guarded. His eyes were open. Um, not always visually connecting with me. Um, family, son and daughter very present at the bedside, trying to, you know, reassure Dad. 'It's okay we're here Dad. We're here. We're just going to move you now.' Dad kind of, 'Ugh, ugh.' You know, looking shocked and kind of uh, guarded with his movements. And then the actual movement from the stretcher to the bed caused pain. Um, now again, I confirmed that with the family, with his history. But I could see that body language showed that it was pain.

David: Um hmm.

So okay, immediately I was going for something [medication] for pain.

David: Um hmm.

I was also going for something [medication] to help him relax, calm down a little bit. Help loosen the limbs. Um thinking about him being in bed for two weeks. And then when I had the opportunity, and only after 25 minutes or so, allowed the analgesia to work, then I went to take a look, you know, to see his skin. Was his diaper dry? Was there anything else going on that perhaps we could have adjusted?

David: Um hmm.

Um, and obviously at the same time, always talking to the person. Introducing who I am, what I'm doing. Trying to be gentle in my approach.

David: Um hmm.

Um, not just touching that person without giving them a heads-up.

David: Um hmm.

You know? About who I am and what I'm doing. –*Registered nurse*

Once patient comfort is attended to, the nurse completes an admission interview, which is often done with families outside of the patient room. The nurse also ensures that various paperwork is completed, by the patient or the family, such as

consent forms that specify that the care delivered here is specifically about “end-of-life,” and pharmacy forms that require a credit card be provided to pay for the costs of medication. The volunteer might give the family a tour of the facility. The physician will visit with the patient, perform a medical assessment, and visit with the family.

From the perspective of hospice caregivers, the time surrounding hospice admission is “overwhelming” for patients and families. Hospice caregivers regularly spoke about how it takes time for patients and families to “settle in and get used to the place,” and for trust to develop between themselves, their patients, and the families.

Patient deaths, meanwhile, occur at all hours during the day and night. When a patient dies, the family is notified if they are not already present. In most cases, caregivers enter the room of the recently deceased patient and together with the family read what is referred to as a “universal prayer”:

We come together at this moment of death to commemorate with one another the life of _____ who has lived with us. Our love goes with him/her, let us now remember him/her in a moment of silence.

The family is invited to light a candle that will burn for the next twenty-four hours in a lantern at the front door of the hospice. When more than one patient has died in the last twenty-four hours, burning candles are placed on the mantle of the fireplace in the front living room. Sometimes families stay at the hospice until the funeral home arrives to collect the body, while others choose to leave before. As the body is wheeled from the room to the vehicle waiting just outside the front doors of the hospice, the doors to the other patient rooms are closed and family members are asked to stay inside. At least one person from the hospice will walk with the stretcher containing the body to the front door of the building, a symbolic act that is about honouring a commitment to have *stayed with* the patient throughout his or her entire stay at the hospice, i.e., “We will not leave you” (Figure 3).

After a patient’s death, the nurse fills out a form, noting the circumstances of the death and the reactions of the family. The nurse also indicates on this form whether a

“quick” follow up with the now bereaved family is warranted, and the reasons for this². This form will be used to structure the weekly bereavement rounds that happen every Wednesday afternoon, during which the entire team discusses each patient that died that week. The following excerpt from my fieldnotes describes the various activities that occur surrounding the death of a patient.

A little past midnight, before the evening nurse leaves, the patient in #5 dies. The night nurse is told by a family member “we think she stopped breathing.” The family had not been present earlier this evening and the evening nurse had called them to update them on the change in condition, i.e., that she now seemed to be imminently dying.

The evening nurse and the night nurses chat together in the hallway just in front of the nursing station. They talk about how the family is doing. They say that the patient was so at peace with her dying, that they think the family will be too. One nurse says that the family told her that it [moment of death] was peaceful, and that this comforted them. The nurses also admire how the patient looks: she has a “beautiful bald head.”

After we finish the first round, the two night nurses go into the room to do the universal prayer and candle with the family. They tell me that her husband said a few words afterward, speaking of her courage and how she will be missed. They are described as a “nice family” to me.

Later, I accompany the nurses as they go in to remove the “tubes” from her body. We enter and the family leaves us alone in the room. The nurses tell them we’ll just be five minutes.

We put gloves on. The nurses take out her subcutaneous needles (one for the syringe driver, one for breakthroughs) and remove her Foley catheter. They reattach her incontinence brief, cross her arms, and straighten her gown. They remove all pillows except for one under her head and re-cover her with the blanket. They gently try to close her mouth but it stays open. One of the nurses rubs the patient’s head affectionately. –*Fieldnotes*

Shared Values and Beliefs of Hospice Caregivers

The hospice opened a decade ago, and many of the hospice caregivers have worked here since that time. Together, they have come to create and belong to a

² The hospice offers bereavement support whereby volunteers telephone family members at one month, three months, six months, and one year after the patient’s death. For certain family members deemed “at risk” for complicated bereavement, they will be telephoned sooner than the one month, hence a “quick” follow up.

collective community that holds specific values and attitudes toward life, death, and palliative care. It is through sharing these values that individual hospice caregivers fit in with the entire team. Newer hospice caregivers quickly come on board with the prevailing values and beliefs that operate here:

And if people don't have those values they find out sooner or later that probably they don't belong working here. –*Nursing leader*

This shared value system sustains hospice caregivers in the work that they do, as they confront pain, sadness, and suffering on a daily basis. Their values and beliefs provide a common framework that informs the support and guidance offered to patients and families facing the uncertainty of their own death experiences.

So what are these values? First, hospice caregivers value all human life as possessing an inherent quality and dignity. For this reason, they seek to help people achieve the most out of whatever time they have left. They focus on assisting patients and families to have meaningful experiences in which they can experience pleasure and love. In the following excerpt, a pastoral care volunteer explains the ultimate significance of hospice is about providing patients with a “safe space to die,” which happens through honouring another’s dignity, personhood, and relational connectedness. This participant also highlights the role of hospice interventions, “to palliate symptoms,” as integral to the creation of such a space.

This place is about giving, helping people to have dignity, or providing them a safe space to die with dignity, and for their families to be with them...

David: Uh, how do you understand dignity?

Dignity is um, being, given the space to be recognized as being fully human even though one is dying. And not pushed off to the side but that their life still has meaning. Their connections, their family connections, their circles of friends, they are all still very much a part of who they are. And allowing for that to happen. And also too with pain control and what not, to try and alleviate, to palliate symptoms that would otherwise not give them some dimension of, possible, of being able to interact with their families. And the world around them. –*Volunteer pastoral care provider*

It is through collectively valuing the inherent dignity of all dying patients that simple acts of caregiving, like brushing a comatose patient’s hair, have moral

significance and become part of the expected standard of care. In this setting, patients receive:

...a lot of attention...full care...two baths in the day...home cooked meals. –*Patient care attendant.*

To care for patients in these ways is about showing them:

...the respect that one deserves. Not being treated unfairly...not being treated like a second class citizen, or lower than a human being. – *Patient care attendant.*

In the following example, a nurse provides morning hygiene care to a dying patient. As she works, she talks to me about what she is doing, and makes visible the ways in which her caregiving actions are purposefully directed toward respectful (i.e., dignity-conserving) care:

During the bedbath, I watched as the nurse shaved Mr R, who is now unconscious. She shaved him because, she says, “I know that was very important to him, to be shaved every morning.” Today is the first day she’s had him, and she does not know what kind of music he likes. She wants to put on something though because otherwise, “When it’s quiet in the room like this, it’s like they’re really alone.” –*Fieldnotes*

Just as hospice caregivers recognize that all life has inherent worth, they are openly aware and reflective about the fact that all life ends. To die is part of what it means to be human, and is therefore not something that needs to be feared. Death is:

...part of the life experience, just another chapter in it. Not this frightening, awful mystery. – *Volunteer*

Hospice caregivers recognize that there is a tension between accepting death as a natural life process and acknowledging the tragic and devastatingly sad situations that their patients and families are facing. In my interview with a physician, she explained that patients and families will feel “robbed” and angry when death comes for them, particularly when the patient is not elderly, and that she understands this. She nevertheless suggested that the good death is more likely when people are able to find peace with their own mortality.

I think that a real nice death is when the patient embraces what happens to him and uh, feels that uh, it’s just natural. Natural, a process that he needs to go through, and it’s not a punishment or we didn’t do this or that. You know some people say, ‘Well, I had a good life,’ or, ‘I did everything right, how come it

happens to me?' Well because it happens to all of us, death is a part of life. –
Physician

Helping others to view death in a similar way, then, to guide patients and families through their fear and towards a place of peace and acceptance in facing their own death experience, is considered a noble caregiving goal in this setting.

If we make it normal, and be there for support, and it'll be ok. It's not frightening, it really isn't frightening. If we think about it, things that are upsetting to us are things that are frightening because we don't know that that's the way it is. It's a first time experience. – *Volunteer*

Comfort.

In this hospice, the meaning of palliative care is fundamentally about making people comfortable. Palliative care is:

...also known as comfort care –*Registered nurse*

The word comfort recurs through discussions within the hospice and is the basis of a shared vocabulary amongst hospice caregivers regardless of role. Nurses, physicians, volunteers, patient care attendants, and housekeepers together hold patient and family comfort as their primary goal.

From the perspective of hospice caregivers, patients and families often arrive to the hospice uncomfortable, and the challenge is to restore the best possible level of comfort before the patient dies. Many patients are admitted “poorly managed,” which usually means that their current level of symptom relief is suboptimal, and they are not currently dying well. The state in which admitted patients arrive is a barometer for the perceived quality of EOLC given elsewhere. Parameters of these judgments include whether the patient arrives in pain, with good or poor skin integrity, and having had (or not) honest discussions with his or her treating team about prognosis and current end-of-life status. Further, the perceived lack of knowledge that the transferring health care professional (usually a nurse giving report over the phone to the nursing team leader) seems to have about the patient's overall situation is often a source of consternation and bewilderment for the hospice nurses.

Attending to pain and bodily discomfort is the first way in which hospice caregivers enact comfort-promoting care. Facilitating another's comfort through relief

of bodily suffering is a means of promoting dignity at the end of life, as explained by a nursing leader in the excerpt below:

You know, it's really important that they [members of the hospice team] do share a certain value system. For instance, one of the main values that pretty much everybody has here is nobody [should] really die in pain, or should be suffering, you know. People deserve that dignity, to not be in pain. –*Nursing leader*

In this hospice, pain is on everyone's radar; all caregivers are on the same page as to the threat and burden that pain imposes on the ability to die well. Hospice caregivers are so strongly committed to eliminating pain that all patients are continuously assessed for pain and are promptly medicated when they request this. As a result of this zealous approach to pain management, pain itself does not seem to overwhelm the ability to work toward the good death in hospice care. In the following reflection, a patient care attendant speaks with me about the conversations she typically has with patients here, and notes how pain does not regularly feature as a main topic of concern.

[In talking about what sorts of things patients speak about] ...Another pleasant surprise is I've hardly ever heard a patient really express a lot about pain. Um, I mean we certainly, they'll certainly say I have pain, and, but you know, they don't go on about it. Like it seems to be managed very well, from what I can see. So that almost seems to be like one of the last things that they seem to be worried about, which I think is wonderful. Because I'm sure that anybody who's diagnosed with a terminal illness, no matter how old you are, this is one of the main fears, is pain. And to have that managed, you're able to do so much more with the time that you have left. –*Patient care attendant*

While comfort is about not being in pain, as described in the excerpts above, it also refers to broader experiences of wellbeing. Bland (2007) explored the nature of comfort in the context of nursing home care using critical ethnographic methods. She found comfort to be a complex and multidimensional experience that includes relief from physical distress, but also benefiting from more general care practices, e.g., "being offered a refreshing shower on a hot summer's day" (p.940), as well as feeling safe, secure, and well looked after through positive and personalized relationships with care staff. This interpretation supports the view that comfort is not just an intrapersonal concept but interpersonal as well (Lowe & Cutcliffe, 2005). Bland further identifies that the routinized institutional model of care delivery within nursing homes ultimately

threatens the ability to offer comfort-promoting care. She writes: "...the task-focused approach characteristic of this culture was such that staff were largely unaware how uncomfortable residents were and the manner in which aspects of their care contributed to that discomfort." (p. 942) In this hospice, by contrast, a defining cultural characteristic is an orientation toward comfort-promoting practices such as those described in Bland's study. For hospice caregivers, helping patients and families to be comfortable is what is most at stake for themselves as care providers. Therefore, a "task-focused" approach does not risk compromising comfort care; responding to patients who are may be uncomfortable is universally acknowledged as the most important task at hand. Comfort underlies all practices of assessment and intervention. When nurses enter the rooms of patients who are awake, they are most concerned with: *Are you comfortable right now?* If yes, then all is well and life carries on. If not, then the nurse will probe deeper into what is making the patient uncomfortable, and ascertain whether she can do something to help: Does the patient need to be repositioned in bed? Does the patient need a medication? Would the patient like something to drink?

Judgments as to patients' comfort also structure team communication and interaction. For example, if a volunteer finds a patient to be uncomfortable and is unable to respond to this alone, she will seek out the patient's nurse. Likewise, continuous judgments about the overall comfort experience of patients provides the content for discussion between nurses and physicians, who are formally updated at least once every day, and throughout the day as well in an informal and conversational manner, by nurses as to the patient's overall comfort.

The extent to which families feel comfortable within the hospice is also an important focus of hospice caregivers: Are they anxious? Do they have unanswered questions? Do they understand what is happening? Are they eating? Are they sleeping? Providing for families' comfort within the hospice includes providing coaching about *how to be* as they face the dying and death of their loved one. Through the relationships that they develop with families, hospice caregivers encourage family members to pace themselves, to conserve their energy, to eat, and to be present in whatever ways work best for them.

They [family] are used to being 24/7, not eating, not sleeping. And suddenly [when they get here] we're saying no, you know you can, you can be with the person [patient], but you can take your breaks, you can sleep, you can eat. We'll make sure that you're well fed. -*Psychologist*

...if they're having problems with dealing with you know, anticipating dying or afraid of what's going to happen to their loved one, teaching them and getting them so that they're comfortable in the situation. And then also allowing them to be who they are. Like if somebody is not comfortable with being at bedside all the time, you know, helping them not feel guilty about that. Cause a lot of families are like that, they'll, they feel like they need to be there but then they're conflicted because they're not comfortable being there. And then on the other side of that coin, there's the families who want to be there all the time and sort of allowing them to you know, be part of the whole process, more so than other families. -*Registered nurse*

While comfort is the primary goal of hospice care, it is also itself a mechanism through which trusting relationships between hospice caregivers, patients, and families flourish.

If you can make the patient feel more comfortable, their trust comes automatically." -*Nursing assistant*

David: Is that important for the family to trust you?

Oh absolutely. That's the whole thing. Because then they, then they feel like, you know, we care as much as they do...you just keep trying your best, your hardest, at making them feel comfortable here. -*Nursing assistant*

Making patients and families more comfortable is a way for caregivers to gain trust, and emphasizing to patients and families an explicit focus on comfort helps everyone to establish common ground from which to collaborate as the patient dies. This process is not always easy or straightforward however, and tension sometimes arises when patients or families do not share the same perspective regarding comfort and comfort-promoting strategies. Such tension often revolves around the use of medication, e.g., a nurse might want to give morphine to a patient who seems uncomfortable but the family resists this assessment and/or the administration of the medication. Tension might also arise from practices proposed in the context of declining functional ability, e.g., a nurse may feel that walking to the bathroom is contributing to a patient's

discomfort but the patient refuses insertion of a urinary Foley catheter. In situations such as these, hospice caregivers work toward helping patients and families acknowledge comfort as a primary therapeutic target and consistently offer strategies by which this can be achieved.

The focus on comfort-care in this setting means that hospice caregivers strive to create an environment that is relaxing: calm, quiet, and serene. Interestingly, this seemed to have a paradoxical effect on some families. The move from acute hospital to hospice can be experienced as an abrupt transition, and some families required time to adjust to an approach to care with which they were unfamiliar. The following excerpt from my fieldnotes refers to a discussion that I had with one such family. In an earlier interaction with these family members, they had expressed to me a feeling of ambivalence around hospice caregivers' *exclusive* orientation toward patient comfort. Patients here are generally not woken when they are sleeping, and this was a source of frustration for this family when they arrived at 11:30 am one morning and discovered that their husband/father had not been woken for breakfast. They told me that they appreciated the extremely tranquil nature of the hospice environment, but they also found this tranquility unsettling. They repeatedly referred to the patient's current state as "critical," i.e., very ill and potentially close to death, and wondered about how hospice caregivers would respond to the patient should his condition suddenly change, given what appeared to be a very relaxed and calm approach to care. Three days later, the family's perspective appeared to have shifted toward embracing a focus on comfort-care, though a certain degree of ambivalence remained:

I start the conversation by asking, "Is he sleeping more?" Ms. M (daughter) says that yes he is. She also notes that he is more confused. She talks about how she and her mother (the patient's wife) are content to let him rest and sleep, but that when other visitors are here these people try to stimulate and interact with him. This is tiring for him and causes his confusion to become more apparent, whereby he says things that "don't make sense."

Ms. M seems to be in a position of regulating these other visitors, in terms of their interactions with her father. She describes explaining to others that her father needs to rest. The visitors apparently want to touch him, talk to him, and give him mouth care. They are eager to *do things* with and for him, instead of just sitting and watching him sleep.

Ms. M's narration seems to evidence a tension between two different perspectives. On the one hand, she describes her perception of the situation in a way that seems perfectly aligned with the hospice ethos– so much so actually that I wonder whether she is rehearsing the same *script* that has been delivered to her by the staff here, i.e., explaining that it is okay to let the patient sleep indefinitely, and emphasizing the importance of not disturbing the patient for the sake of his *comfort*. Ms. M explains that she and her family were given written information about the stages and signs of the dying process by their nurse. She says that she has shown this literature to visitors, so that they would better understand the situation. It appears that Ms. M is using the hospice literature to align her visitor's perceptions with what is 'normal' for a patient in this condition. This is very interesting because she seems to be mirroring what the nurses have done and are doing with her and her mother. On the other hand however, Ms. M remains uncertain and somewhat uncomfortable around unanswered questions. Her "major preoccupation" is that her father is not eating or drinking anything, and she makes several references to having asked the hospice staff about whether he shouldn't be receiving artificial hydration (which she refers to as "solution," pointing to her arm). She says she understands that hydration would "prolong" her father's life, and that this is not her goal, but she nevertheless worries that not eating or drinking anything is harmful to the body.

Ms. M tells me that she expressed her anxiety to the hospice staff. What if his breathing changes? Will they supervise more? Again, as in our first meeting, she uses the word "critical" to describe her father's condition.

My interpretation of this interaction is that while Ms. M wants her father to be comfortable and is appreciative of hospice caregivers' assistance in providing for this, she still feels that her father is to a certain extent "left" to sleep undisturbed, and that it is somewhat unsettling to just "watch" without doing much. She seems to be engaging in a process of *watchful waiting*, which for her entails a strong element of *vigilance*. She is attentive to moment-to-moment changes in her father, e.g., he made "a noise" yesterday in his throat – did this mean he was choking? Ms. M describes that he is more "calm" today, where yesterday he would raise his arms in his sleep. With respect to moment-to-moment changes such as these, Ms. M says the nurse "reassured" her to not fixate on every little movement, that overall her father is "peaceful." – *Fieldnotes*

The above fieldnote excerpt shows how I came to understand that families in this setting want their loved ones to be comfortable, but that coming on board with comfort as the primary and exclusive focus of care can be unsettling, and therefore requires a careful process of navigation and negotiation within the hospice caregiver – family relationship. Indeed, cultivation of therapeutic relationships with family members is another shared value of hospice caregivers, and is discussed next.

Family-centered care.

It is a prevailing belief here that how a person dies is important to family; a good death experience impacts on families' own wellbeing and can make a positive difference in their bereavement. This belief arises, in part, by hospice caregivers having had their own personal and transformative experiences with death and with grief. Several hospice caregivers were forthcoming in sharing these experiences with me, explaining how these had been influential in their decision to work in palliative care. For example, one nurse described the following:

...when my mother died ... I went through it all myself alone. And it was very hard and it tore me apart, damn near killed me and, quite honestly. And I had nobody reaching out to me. And, I am almost here, um, I'm very happy to be here to help the patient ... But if I can help a family member. Get through this. For me that really is what brought me here, is the, I don't want to see, or hopefully, do my best to involve myself to help them move through this and make it um, a life changing in a positive way, without them having to go through the hell I did. –*Registered nurse*

Care for family as a distinct locus of attention is important to these hospice caregivers, they understand supporting families to be an inherent aspect of their role.

...it's part of our work to be with the family. To give time. You know? [On evenings] we're the staff dealing with family. Which is fine for me. It's part of the deal. –*Nursing assistant*

...people come here exhausted, the [family] caregivers are exhausted. And it's so important that we pay attention to them as well. And it's probably been a very long time since somebody even offered them a cup of tea...even those tiny small things like a cup of tea, are hugely important and make a difference in people's lives. –*Volunteer coordinator*

A large amount of space within the hospice is devoted to family comfort and/or support. While patients spend most of their time in their room, if not in their bed, ample space outside of the patient rooms is available for families to rest, to socialize, and/or to receive support from hospice caregivers. These spaces include the outdoor patios and dining area, the front and rear common areas, and the library. The library is a particularly interesting space because it is here that hospice caregivers and families can meet in complete privacy with the door closed.

In this setting, hospice caregivers make use of these spaces and *sit down* with

families. This theme of *sitting down* recurred through the hospice caregiver interviews, and was repeatedly apparent throughout my observations. When patients are admitted, both the nurse and the doctor (separately) sit with the family, often at one of the many tables in either the living room or parlor. Sitting down in this setting is also spontaneous, happening in the moment. Such spontaneity appears to be an important feature of family work that is made possible not only through the architectural layout of the hospice but also through the time available as a result of the high nurse-patient ratio. In the following example, a nurse speaks to me about caring for families in the context of a patient being sedated for agitated delirium. She emphasizes the importance of sitting down, in the moment, with families in order to help them through such a situation.

David: Do you find that there's ever an ambivalence, within family members or anybody else, in terms of the sedation?

... I think there's been a couple of situations where we've had family members saying, "Look, like I don't want him like this [restless and agitated], but I'd like to be able to talk to him." But then you really need to sit down, have the talk about finding a good balance, and that's what we're here for. We're not, our motive isn't to wipe him out, asleep. We want you to have those moments, but we have to find a good way to do it. –*Registered nurse*

Care for the family is also apparent through the highly organized bereavement support that is offered following patient death. During the patient's stay, families are invited to provide their contact information for bereavement follow-up. This involves four supportive telephone calls from a volunteer during the first year after the death, at one month, three months, six months, and the one-year anniversary. During weekly bereavement rounds, families are identified as to whether "regular" follow up is appropriate, or whether a "quick" follow-up might be required. According to the psychologist who coordinates the bereavement services offered, reasons for a quick follow-up might include a very short length of stay, "quick admission, fast demise"; difficult death, "breathing gasping moaning issues"; or complicated dynamics, "dysfunctional families." All of these factors are believed to predispose families to requiring more support during the bereavement period. Another bereavement support is the memorial service, which is an evening ceremony held at the hospice every three

to four months to which all bereaved families from the preceding period are invited. Additionally, the hospice coordinates bereavement support groups in the community. These are open to the public but many participants are family members whose loved one died here. Provision of bereavement supports such as these are felt to be important in ensuring that care of the family does not end abruptly with the death of the patient.

David: What would you say is the purpose of the support calling?

Uh, mostly for the family members to know that, you know, they're not on their own. They're not just, they just finished saying goodbye to their loved one. And they're saying goodbye to a lovely, warm, nurturing place. And out there in the cold cruel world, no, they will be supported, and listened to. – *Volunteer*

That the unit of care in this setting includes the family is also evident in hospice caregiver descriptions of what it means to work toward a good death. Such descriptions interweave notions of family wellbeing together with notions of patient comfort. In this way, the good death is conceptualized as a phenomenon of the whole family.

David: What is this place all about?

...it's heaven (smiles)...it couldn't be a better place for patients and family, um, to be when they face terminal illness, um, and also to die in dignity...to get privacy, to get looked after, not only the patient but also family, to get space. – *Social worker*

...it's [a good death] if the patient and family sort of get what they want out of it... and if, if I can help that family to, and that patient to transition, again smoothly, and support them along the way. – *Registered nurse*

A good death to me means a family of the person who's dying... that they're serene...That they can be here and enjoy the place. That they can be, that they can take with them a wonderful memory from being here...They remember being here and being cared for, that's what people will remember. – *Nursing assistant*

Creating “wonderful” memories for family in the face of death is not uncomplicated. It involves the hospice caregivers maintaining concentrated focus on the family, continually assessing their wellbeing and engaging with them to facilitate experiences that can be interpreted as *good*. Knowing the family happens through team communication, such that a collective understanding is built. Through informal

conversations that occur between hospice caregivers during a typical day, and through formal discussions, i.e., weekly rounds and change-of-shift reports, families are discussed in detail. The team comes to appreciate the family's dynamic and the most salient issues at play. Examples might include knowing which daughter lives in Florida and when she will be arriving, or which sister is having a particularly hard time because she is also caring for her ailing mother-in-law. Through team talk hospice caregivers reflect on how the family is coping, what supports they might benefit from, and whether they are at risk for complicated bereavement.

Weekly team rounds discussion of Ms. C: It was the patient's birthday yesterday. "That was hard for the family." Ms. C's parents are divorced. They are more comfortable apart so they trade off visits in the hospice room. Her father is having a harder time than her mother. He is grieving also for everything he's missed with his daughter. His wife also has cancer. He is felt to be more "at risk." At the end of the team discussion, the group reflects on how "sad" this whole story is. *-Fieldnotes*

As a focus of care, attention to family member needs and interests takes work. Families requiring special attention step up the busyness of the care environment. On evenings when hospice caregivers are staying later than usual, or when hospice caregivers complain over a period of several days or weeks that the hospice is busier than normal, this is sometimes attributed to the needs of particular families.

The MD is here when I arrive at 8:15 pm. She says, "It was crazy today!" "Busy?" I ask. When she says yes I ask what made it busy. "Oh, the families!" she says. *-Fieldnotes*

When patients experience distress, families are seen to suffer. The challenge then is for hospice caregivers to connect with family and support them through traumatic events and experiences. Support in this sense is offered first through committed attention toward the patient's wellbeing. In this way family sees that the hospice caregivers are doing their best to provide for their loved one's comfort. At the same time, support is offered directly to suffering family members. Hospice caregivers make themselves available to listen, hug, and cry with grieving and frightened families. They are there to hold families as their world falls apart, and help them to integrate what is being lost with what lies ahead.

The nurse tells me she is going to Mr. L's room to "check on how things are going." She walks through the patient's room to the lawn outside, where the patient's spouse, Mrs. L is standing, surrounded by many other friends and family members. The nurse goes straight to her. They share a knowing glance. The nurse touches Mrs. L's cheek and they hug. Mrs. L says she is relieved that it is this nurse who is with them today. The nurse listens as Mrs. L tells of feeling she will "not be able to live through" another night like the last, during which Mr. L was confused, disoriented, restless, and agitated. She describes feeling reassured that he is now "peaceful." Back in the room, the nurse checks on her patient. He seems to be in a deep sleep. His mother is seated beside his bed. The nurse speaks to his mother, tells her that her son can hear her, that hearing is last of the senses to go and that she should speak and tell him whatever she has to say. Mr. L's mother seems relieved by this. She says that's what she had been wondering. She is tearful. The nurse, who had been on the opposite side of the bed, nearest the door, checking Mr. L's syringe driver and caressing his arm, comes around the bed to stand next to his mother. She gives her a hug. -*Fieldnotes*

What matters most.

Hospice caregivers believe that the end of life is a time to focus on what matters most, and to this end they strive to provide a space for patients and families to do this. This is a value that is echoed in wider palliative care discourse. Consider for example Byock's (2004) emphasis on the four things that matter most in life: "Please forgive me. I forgive you. Thank you. I love you." (p.3). From the perspective of hospice caregivers, the end of life is a time for coming together in positive ways and for saying goodbye. It is not the time for bitterness, anger, or petty concerns. This value is communicated to patients' families, as in the following notes taken from observing a psychologist give support to the husband of a patient who was currently experiencing tension in his relationship with his sisters-in-law.

As the psychologist and I are talking with Mr R [whose wife died the next day], he mentions his previous experience of losing his relationship with his brother over his mother's estate. The psychologist, without missing a beat, replies, "Well, as all of us here know too well, life's too short for that." -*Fieldnotes*

Hospice caregivers often find themselves working with families that do not seem to focus on what matters most in this way. Hospice caregivers will often refer to tensions within families that are beyond their reach or control. Families will sometimes be labeled as "dysfunctional," meaning they are judged to have psychological, social, or

other therapeutic needs that extend beyond what the setting is equipped or mandated to provide. Working with these families does not seem to be as motivating or gratifying for hospice caregivers.

A nurse admits a patient into #5 today, and the team discusses this case. Apparently there is a long history of very complicated family relationships – tensions, fighting over money, suspicions that “the vultures are circling” with respect to the patient’s imminent death and future estate. In response to this discussion, another nurse says, “Death, like nothing else, really magnifies the bullshit” to which the admitting nurse replies, “It just makes me sick!” At change of shift, the admitting nurse gives report and seems very animated, anxious, and frustrated when describing her admission in #5. She sarcastically describes handing over this patient and family to the evening shift as her “gift” to them. - *Fieldnotes*

Hospice caregivers acknowledge that patients and families come to the hospice with a lifetime’s worth of relational history and complications. Thus, while they believe strongly that creating spaces for patients and families to come together in healing ways is part of facilitating the good death, they do not take responsibility for the patient and family’s own emotional issues.

Sometimes there are other issues, there are issues with families, we can’t fix everything. –*Registered nurse*

Like some, you always have like family issues with some families that might not be taken care of before they go [die]. –*Patient care attendant*

Collaborative engagement.

While responding to family members’ own needs for support is an important end in itself, collaborating with family is also a way to achieve optimal care of the patient. Collaborative alliances between family and hospice caregivers are especially important as patient consciousness fluctuates and declines over the course of dying. That dying patients eventually become unable to express their agency is inevitable. Therefore, as Hadders (2011) notes, “The social identity, personal integrity, and wishes of [uncommunicative terminally ill] patients depend on staff and relatives for safeguarding and maintenance” (p.223). Part of creating a safe place for dying, then, involves family and team working together toward mutual goals of patient comfort and optimal palliation.

...in trying to determine whether the patient is uncomfortable, uh often times

the family can tell us if we can't. Sometimes they say, 'Oh he never did this before and all of a sudden he's doing this.' So that gives us an idea that something is going on here that we need to, uh we need to tackle, we need to look after. –*Registered nurse*

When patients are admitted from home, their family caregivers have been responsible for much of the instrumental tasks of caregiving. Thus, on admission they are seen to arrive “exhausted.” Further, when patients are admitted from hospital, family caregivers have often had to spend time “advocating” for their loved one’s basic care needs. These families sometimes feel that their loved one has suffered a certain form of neglect as the result of hectic and chaotic care environments in hospital that are plagued by staff shortages and inadequate knowledge of palliative care. In both of these scenarios (admissions from home and hospital), hospice caregivers create the safe context for dying by committing to take over all instrumental tasks of caregiving, e.g., bathing, turning, bowel management, dressing changes, as well as to provide optimal symptom management, so that family members can just *be* with their loved ones. In this way, family members here are situated as *clients* of care (Stajduhar et al., 2008). Families are:

...encouraged just to sit back and just love them, hold hands and love them. –
Volunteer

The rationale for encouraging families to situate themselves in this way is so they can focus their time and energy on being together in ways that will foster a good death, e.g., having conversations, saying what needs to be said, while the patient is still able to communicate. Ultimately, it’s about providing families an environment where:

Here you’ll have an opportunity to be a spouse again, or a son or daughter again, or a family member again, rather than just the caregiver. You’re still a caregiver, but you have extra hands and feet here now to help you. So you can spend more time now being that partner, being that whatever. And it’s interesting to watch the facial expressions sometimes, when I’m not the only one that says that, some of my fellow team members will mention that too. And you see almost a physical [exhales deeply] that happens, I’d say I see it more often than not. –*Volunteer pastoral care provider.*

Another rationale for positioning families in this way is that when families “sit back” and allow hospice caregivers to take over the clinical management and nursing

care of the patient, they are able to deliver, without challenge, all interventions they feel are appropriate and necessary to provide for the patient's good death. Conversely, some families resist "sitting back," insisting instead on participating in the planning, organization and implementation of the patient's care. Refusal to relinquish these aspects of caregiving can cause strain in their relationship with hospice caregivers. Hospice caregivers, for example, might interpret that a family's vigilant monitoring of the nursing care means that there is a lack of trust.

Sometimes people are angry, and they're suspicious and they're mad and they're checking everything you do. And they don't trust you, and you know, they're second-guessing everything. –*Nursing assistant*

They're trying to micromanage everything, so used to doing it at home, and then it's harder for the medical staff to do some of the work, because they're constantly over [their] shoulder, [saying] 'Why are you doing that?' 'What are you doing that for?' Not just curiosity, it's like, 'I don't trust you.' – *Volunteer pastoral care provider*

Hospice caregivers are likely to interpret such families as violating important boundaries that they feel need to be respected. For example, it is hospice caregivers, not family, who prepare and administer medications in this setting. It is hospice caregivers who will perform specific procedures, regardless of whether family expresses a willingness or desire to do so, e.g., bowel disimpaction. Families who do not adhere to these boundaries are more difficult to engage and collaborate with, and are experienced by hospice caregivers as undermining the established social order of the hospice. In the following interview, a hospice caregiver describes how this order is subverted when family members step outside of their "role" as clients of care and encroach upon the roles of hospice caregivers.

David: Do you ever find that there's friction between the patients and the staff, or between the families and the staff?

[pauses] Um friction, well, it's funny that you're asking that question. We just lost a patient um, actually it was yesterday, circumstances were, well she was the mother of two daughters, who are nurses...

David: Right, this is in number __ right?

Uh yes exactly. And being young nurses, so they'd been caring for their mother

when she was at hospital, even doing things like disimpacting their mother, which I thought was a little, going, you know breaking, can you say boundaries there?

David: Yeah, yeah

So when they first came here they kept that role as nurses, you know they were not acting as daughters but nurses. Make sure that, they would come and either come in the nursing station, go in the med room and say well my mother's due for this, or she needs to be put in a Hoyer lift, or they were really, the one speaking for their mother like. So of course, well of course, it ended up with, I shouldn't say friction but, maybe a little tension between our staff, our nursing staff and them because of that. Because those girls were, you know were um, not respecting boundaries, and they were going a little over their, what they were supposed, their role actually as daughters but just being nurses. So we had actually a meeting involving, I was asked to attend a meeting with [managers], with [one of] the daughters. And uh, about mentioning that maybe it was time for them to just drop the role as nurses but being the daughters. So it was difficult for them to let go of that role. But I think towards the end in the last, past week actually they sort of mellowed, and were more cooperative, yeah cooperative in a way. Like they were letting the staff doing things and uh, you know keeping to, yeah. So I wouldn't call, friction or tension in that sense, they didn't know where the boundaries were, and they were just, you know doing, yeah doing...that role which they should have dropped or, when they got here. –*Social worker*

Pleasure.

The good death involves the ability to enjoy pleasure from being alive. To this end, hospice caregivers value the potential that a seemingly little thing, like a dry towel or a delicious breakfast, can bring comfort and satisfaction to someone who is terminally ill.

I tell the ladies [volunteers] who work in the laundry for example, I say we could have the best doctors in the world, and wonderful caring nurses, but if we don't have a dry towel to give somebody, so we're not doing a good job. So I see all those things as coming together, as being part of the puzzle that creates a good death. So all those comfort things. And whether it's a dry towel or getting your egg made just like you like it so you can enjoy that one more time, all those things contribute to a good death." –*Volunteer coordinator*

Caregivers here are happy and proud when they succeed in helping a patient to enjoy some small pleasure, for example helping a patient to smoke a cigarette, or bringing a patient a cold beer or a cold milkshake. These practices are about more than

making patients feel good, although this is important. These practices are also about affirming the patient as a human being, capable of feeling pleasure and participating in his/her own life to the extent that is still possible. When patients can no longer participate in such experiences and/or are no longer conscious, nurses still work toward conserving their personhood and their dignity by personalizing care in ways that they imagine might provide pleasure. For example a nurse might use red wine to moisten the mouth care sponge of a patient who loved red wine, or use a syringe to drop Coca-Cola into a delirious patient's mouth who spontaneously starts mentioning "Ice cold Coke!" In the following example, a senior nurse orients a newer nurse to this value of fostering dignity and personhood through attention to the individual likes and dislikes of hospice patients.

I follow the nurses around at the start of this evening's shift. We arrive at Mrs. V's room. She is unconscious, and there are no visitors right now. One of the nurses, who started working here a couple of months ago, is about to do mouth care. The other nurse, who has worked here since the hospice opened ten years ago, tells her that it is important not to use tap water. She empties the cup at the bedside and fills it with water from the cooler outside of the room. She explains that Mrs. V, being from the country, *hated* tap water, as she had previously said she could taste the chlorine. For this nurse, it is important to affirm and respect this preference for the patient, even now as she is currently comatose. -
Fieldnotes

While working in a context in which suffering, grief, loss, and death are continuously encountered and are beyond control, hospice caregivers' focus on "little things" like cigarettes, milkshakes, wine, beer, and even the taste of water, is an important mechanism to keep the faith that what they do matters and that they can in fact make a positive difference. In the following example, a nursing leader talks with me about learning of a particular patient's love of football, and providing for his good death through knowing this about him.

The nursing leader mentions to me that the hospice director had arranged for the quarterback of the [local CFL team] to visit Mr. W, who has been having a very hard time recently. Apparently he's a big football fan, and this visit went very well. He had had a hard day and this seemed to lift his spirits. I reflected to her what an interesting thing to facilitate for somebody, and she replied, somewhat sadly, "Well there's not much we can do for him, that's something we can." -*Fieldnotes*

Rescue.

The relationships that hospice caregivers form with patients and families provide the social fabric of the hospice as a safe place for dying. Patients and families repeatedly expressed to me the confidence they felt in their hospice caregivers. They were reassured that these caregivers had expert knowledge of the dying process and how to care for them in the best way possible. Further, the hospice's small size and excellent staffing instilled a sense of security, where patients and families knew that a nurse was always available at a moment's notice, and knew where to find them whenever needed. Almost invariably, patients and families described to me their perceptions of this setting through comparison to previous stays in hospital, contrasting the 'business' of a hospital ward to the calm, quiet, and peaceful environment of the hospice. Further, nurses sustain the habitability of the hospice for patients and families through their daily interactions with them. As one family member commented, "You can tell that they enjoy their work." Interactions between hospice nurses and patients are warm and tender. This warmth and tenderness is conveyed through touch and through voice, nurses are not shy to talk to or touch dying people with love and affection. When visiting with patients, nurses will caress their cheeks or run their hands through their hair. They speak softly, usually calling patients by their first names. When patients and families are talking to the nurses they receive their undivided attention.

After report, I accompanied the nurses and patient care attendant on their "first round." We went into every room. Patients who were awake had their pain assessed. My overall impression from these rounds is the nurses were very warm, quiet, and proceeded at a relaxed pace. In one room, one nurse was checking a syringe driver while the other gently caressed an unconscious patient's face and brushed her hair back. In another room, one of the nurses hugged and kissed a patient. –*Fieldnotes*

The hospice defines itself through its ability to provide high quality, compassionate care to dying patients whose needs no longer align with the priorities of mainstream medical care, but who can no longer stay at home. One participant stated that the hospice was developed out of disillusionment with general hospital care for the dying in which:

...there was no privacy, there was no pleasure, there was no quality of life, there was no time for family resolution” – *Psychologist*

Patients are admitted here from a variety of contexts. There seems to be a mentality shared by hospice caregivers that they exist to *rescue* patients and families from worse dying that would occur elsewhere, especially in cases where patients are admitted from hospital. On my first day at the hospice, one of the nurses told me that she would “never again” work in a hospital environment after working here. Over time, I came to understand that a defining feature of this place is its identification as *not a hospital*. Hospice caregivers often invoke ideas about hospital dying and hospital care as an illustration of the positive alternative that they have created. The hospital environment seems to represent to these hospice caregivers the very elements that threaten good dying: staff shortages, crowded departments, no privacy, and excessively medicalized clinical management.

...you know I went twice to the [hospital across the parking lot] to see patients that were supposed to be transferred... I said, ‘Oh it’s awful, the condition! [gasps] The poor patient.’ And you will see the family sitting in a little chair. The poor lady, it was an older lady, and I say, ‘My God they’re coming to heaven here.’ -*Physician*

...it [hospice] is made to feel like a very pleasant, unlike the hospital where you hear the gurneys going up and down the hallways, and the noise and the confusion, and things like that. You can see just from looking around [here], it’s made to look and feel like a home. -*Volunteer*

Most [patients] are really thankful to be out of the hospital, and no more poking and prodding and invasive treatments that aren’t going to give them much quality of life, or extension of life, by the time they get to us. -*Psychologist*

One participant stated that working here is about “offering a refuge from the activity that you find in a hospital,” and went on in the interview to describe that:

...we see people who come in and are exhausted first of all from the chemotherapy, the radiotherapy, the surgery. Uh, the, ok this chemo hasn’t worked, we’ll try this chemo, we’ll try this chemo and, they come in and they’re totally washed out. And they’ve been usually in a room where there’s four per, four other patients with them, and you know sometimes they come through emergency and they’re totally exhausted. They’ve been fighting, and they’ve been given hope all the time, and that’s what oncologists and surgeons usually do, ok? They’re artisans of hope. There’s nothing wrong with it, that’s what

they do, and that's what maybe they should be. But the letting go, is often times not well done. There's nothing else I can do for you is usually the answer that the patients receive, and then they really feel all alone because then they're totally helpless, they're naked. Ok? They've been exhausted of everything because they've been true good soldiers and done everything that the doctors and the nurses and the technicians and the radio-oncologists etcetera etcetera have asked them. And all these treatments have kind of depleted them, and the cancer is also depleting them usually. So, when they get that message of, there's nothing else we can do for you, they're, they're, can you imagine somebody saying that do you? The message is, good bye. Closing the door. -*Physician*

In this excerpt, the role of hospice as ensuring that dying patients are not *abandoned* is highlighted. Recall from Chapter 1 and the discussion of Cicely Saunders that hospice philosophy was meant to provide “a middle way between too much and too little treatment” (Clark, 2007, p. 432). Thus, the notion of hospice as providing for the *rescue* of dying patients is about ensuring that they will receive compassionate and competent medical, nursing, and social-spiritual care and attention, despite the inevitably terminal nature of their disease.

Pride and privilege.

Hospice caregivers are proud of what they do and what they stand for. Some of them come to professional palliative caregiving or volunteer work through personal experience with death and dying. Some have had to field questions from family and friends about how depressing or demoralizing it must be to work with dying patients. Yet hospice caregivers are happy to be here; the hospice is a

...dynamic, living, [and] joyous place. -*Physician*

A shared ethos is evident. Hospice caregivers are here to provide a safe context for dying in which patients and families have the best possible chance of achieving a good death. They are here to help patients and families make the most out of a bad situation, to provide them time and space to focus on what really matters, and above all, to promote comfort. Hospice caregivers feel privileged to be able to help people in these important ways.

David: What is it like to provide care for people here who are dying?

I've never actually thought about it. You just do it... But for me I feel it's an honour, to be there to help them, in their journey, in their experience here, if that's what you can call it, you know. Whether it's day one or the last day. I feel

privileged to be allowed to help them, touch them, be with their family. It's, it's wonderful...I feel, um, it's very emotional, it's privileged, it's as intimate a form of nursing ...to me that you'll ever have with a family and a patient, it's this. It's extremely intimate. –*Registered nurse*

I just feel like super privileged to be a part of this, I don't know if you can say miracle of life, but it's the opposite of being born, it's death, but it's an amazing part of life too. –*Nursing assistant*

Nurses are proud of the fact that patients do well as a result of the nursing care that is provided: patients do not develop pressure ulcers (though they often arrive with them), they eat well when able and desired, and all of their basic needs are judiciously attended to, e.g., hygiene, bowel and bladder function, mouth care. All of this care relates, from the setting's perspective, to preserving and fostering dignity of patients at the end of their lives. The nurses are proud of providing this style of "basic" care that tends to dimensions of experience that they feel may be neglected in other care contexts. Some of them say that the work they do here satisfies the original reasons they entered the nursing profession. The nurses here are able, and indeed expected, to attend to their patients' basic needs and form relationships with them in the process. Their time is not taken up with other more medical or administrative tasks that they imagine would be the case if they worked in a hospital or a nursing home.

This setting also prides itself on an ability to help patients and family members create for themselves whatever a good death involves from their own perspective. There have been a few paradigmatic good death narratives that are retold by staff that reinforce their sense of assuredness that what they do matters and that they are good at it. Examples include setting up a baby's crib next to a patient's bed so that the dying father and his newborn baby could be close together; enabling a patient who wanted to die outdoors to do so; helping a patient to exit the hospice so he could have "one last drink" with his friends at a local tavern, and turning the dining room into a party space so that a patient and family could host a get together for extended family and friends in celebration of an important birthday.

Over the course of my fieldwork, I was amazed and inspired on several occasions at the lengths hospice caregivers would go to facilitate a good death. For example, one patient was imminently dying during a weekday while his ten-year-old son was at

school. In advising this man's wife that her son should be here for his father's death, hospice caregivers volunteered themselves to drive with her to pick him up from school, or to drive to pick him up themselves if she did not want to leave her husband's side and there was no one else available. The patient's wife did leave to go pick up her son, and the patient died soon after they returned. Later that same day, a nursing assistant spoke about this case during our interview.

...we'll talk about him today. Um, I, I knew because, from what the wife was telling me about the patient in room __, and even though he never spoke to me [the patient had a brain tumour and was not ever verbally communicative while at the hospice], um, you still had the visual, the facial uh, not grimace but the nodding, and the acknowledging and all that. He wasn't ready. He wanted to fight for that ten-year-old boy that they have.

D: And you knew this because, because of the communication that you had with him, even though he wasn't able to verbalize?

Yeah. Just, you'd show him pictures of his son – ah! You know? He'd go and touch the picture and he was very, and after spending time with the wife she said they did everything. Him and the son did everything, she said, 'The only thing my son hasn't done with his Dad is bungee jumping. Every activity, they've done.' So, this morning, I was talking with the doctors and I said listen, I had arranged for my breakthroughs, and I decided, and I told the doctor I went, like I had a range from three to four [milligrams], so I gave the four of morphine. And my [midazolam], instead of one, I gave two. Cause I felt he was still awake.

D: Uh huh

And his breathing. And you could see his brow was furrowed, his eyes were closed but just half closed. And he was breathing very rapidly.

D: This was this morning?

[Nods yes]. And I told him, I said, I said his name, 'It's [me]. Don't worry. I'm going to try and do what I can, to make this the best possible way I can for you. I will try with some medication to make it peaceful. Because I can see the way you're breathing, you're distressed.' And listen, he breathed faster after that.

D: Ok. After you said that?

Yes. So he wasn't able to nod. He wasn't able. So I went and I... I spoke with the

doctor and she says, 'No I agree with you.' He was, we call it, he was too light³.

D: Uh huh, uh huh

I went back and he was congested. I gave him the scopolamine [an anticholinergic medication that is given to dry respiratory secretions in imminently dying patients]. And uh, then I said to the wife, 'You have to go get your son.' And you see everything you know was fine. I mean the son was here maybe an hour, an hour and a half, and he passed away. But you know sometimes, you as, because you've had him a few times, and you've discussed, and there was a trust. The wife said she trusted me because I cared. She, she saw that, the way I was with him and her, I cared. So she trusted me, and she told me a lot about him and her, and relationship, and with the son and all that. So this morning I told the patient that. I said, 'From what [wife's name] said, you trust me. So let me,' and I use that ... And I'll tell the families you know ... 'I'm not gonna push his death ahead of time.'

D: Uh huh

'I'm just gonna make the passage to the death peaceful, as best as I can with the tools I have.'

D: Uh huh

That's what I say. And a lot of the times, I did a lot of reading because the congestion, uh, bothers the family a lot.

D: Uh huh

And after reading ... I've said to them, 'They don't feel it. It doesn't bother them. It bothers you. But not them.' So then, the families say, 'Ok.' ... You know? But with him, for the son's sake, even [the physician] said, 'We want him dry as much as possible.'

[Elsewhere in the same interview]

Like, she's happy today the wife of the patient, because he wasn't struggling,

D: Uh huh

³ 'Too light' is a phrase used by hospice caregivers to reflect that the depth of a patient's sleep (unconsciousness) when he or she is very close to death appears inadequate. These patients are actively dying and appear uncomfortable because they are not sleeping soundly enough. The response to such patients is usually to administer sedative medications to increase the depth of sleep and, presumably, make them more comfortable.

And this morning he was congested.

D: uh huh

And she says, 'Oh my son, I don't want my son to hear that.' I gave him scopolamine, and he was clear, clear, clear, when the son came. –*Nursing assistant*

In this passage, the multiple efforts by this nurse to create a good death are clearly visible: advising the wife to pick up her son, relieving a patient's perceived suffering through sedation, and creating a peaceful image of embodied wellbeing in dying by treating respiratory congestion. The enactment of all of these strategies happens in the context of a trusting relationship that seems to have developed over time between the nurse, the patient, and his wife. This relationship enabled knowing the patient as a person and appreciating aspects of his lived experience, such as recognizing the love he had for his son and the activities they enjoyed together. This relationship was solidified, according to this nursing assistant, by the patient and family's recognition of her caring attitude and actions. This case is prototypical of the pride hospice caregivers feel when deaths go well, as a result of the work that they do.

Qualities of a good hospice caregiver.

In this setting, hospice caregivers hold each other to a certain standard that is informed by their shared value and belief system as outlined above. To meet this standard, hospice caregivers need to evidence that they are 1) mature, 2) compassionate and 3) knowledgeable. These three qualities were discerned through conversations with nursing leadership, as well as asking study participants about "what it takes" to work here.

Maturity in this context means having the courage and the ability to engage authentically with situations of personal tragedy and suffering, and to bear witness together with patients and families. Repeatedly journeying with very sick people who require a great deal of physical and emotional support and who invariably die can be draining. Maturity therefore also means recognizing the personal toll that this work exacts and summoning the resources to take care of self and colleagues to ensure caregivers' own wellbeing. Maturity also involves having sufficient life experience

and/or personal wisdom to be able to engage with people at times of great vulnerability and to create a safe environment for them to live their own loss. Many hospice caregivers have experienced situations of dying in their own lives, and they bring the insights they have developed through these transformative experiences into their care of others facing death.

Compassion means personal investment. The compassionate caregiver recognizes what is at stake for the other and makes this the focus of her moral attention. Compassion happens when caregivers genuinely care about the wellbeing of patients and their families, and make this caring *visible* through relational action. Thus compassion is not just a feeling, it is demonstrated behaviour. Patients and families *feel cared about* by the hospice caregiver who is successfully compassionate.

Knowledgeable means having command of the techniques of symptom management and optimization of comfort along the trajectory of dying. It means having a clear sense of what the road to the good death might look like and the ability to anticipate bumps along that road and to navigate accordingly. The good caregiver *knows* that relational, emotional, and spiritual dimensions of wellbeing in dying are as important as physical comfort. The good caregiver also *knows* the tremendous value to dignity and wellbeing that such acts as brushing a patient's hair, shaving them, being with them in silence and listening when they want to talk, can have. The caregiver therefore organizes and prioritizes her care accordingly. Knowledgeable also means skill in relational interaction with patients and families. The good palliative caregiver knows how to explain things to patients and families. She knows how to adjust her own mood and style of interaction to match the situation. She also knows how to talk people down who are scared or angry.

A mature, compassionate, and knowledgeable caregiver also has common sense, is creative, is a critical thinker, and has good assessment skills. In situations of great suffering or distress, she does not panic but rather remains calm and conveys confidence. Confidence is important when journeying with people who are anxious, exhausted, fearful, or mistrusting. The palliative caregiver seeks to inspire trust in situations that appear to families as foreign and horrific, conveying an attitude of: *This is ok. We know what this is. We know how to handle this.*

A good caregiver is flexible and open to meeting people where they are 'at', and honours the diverse ways in which people will choose to live through their own situations of dying and death. At the same time however, the hospice caregiver has specific ideas about what a good death can be, learned through her experience of working with countless patients and families facing similar situations. In the very short time available between admission and death, the caregiver seeks to provide for a good death by educating the family and inviting them to come on board with what is possible, and to relinquish what is not.

Summary

In this chapter I provided an overview of the hospice, describing the people who inhabit this setting and chronicling the activities that occur daily in the work of hospice caregiving. Hospice caregivers have created in this hospice a lived culture in which certain values and beliefs are shared and propagated. These include the value that all life has value and that all life ends. Death is normal and need not be feared. Suffering in dying can and should be alleviated. Hospice caregivers sustain a specific and exclusive focus on providing comfort and pleasure to dying patients and attend to family wellbeing through family-centered care. They offer their space as a refuge from options for worse dying in mainstream care contexts. Through their perceived ability to make death good for patients and families, they feel pride and privilege in what they do. They hope to provide for patients and families a safe place in which they can focus on what matters most before life ends.

Chapter 5: Working Toward the Good Death in Hospice Care

Introduction

In the previous chapter I presented material that begins to address the first research objective of this study: *Articulate an emic perspective of hospice culture to interpret the practice of nurses and other caregivers in their facilitation of good deaths for terminally ill patients and their families.* Continuing with this objective, this next chapter now looks more closely at the notion of a good death in this setting. Specifically, this chapter examines in more detail what hospice caregivers mean when they talk about “good deaths,” and explores specific dimensions of influence that shape the fostering of good deaths for the patients and families in their care. The material presented in this chapter was discerned during data analysis by my questioning: What influences working toward the good death in this setting?

Good Deaths, Bad Deaths: An Action-Driving Ethic

The good death is an explicit orientation in this setting. Hospice caregivers employ the language of the good death in their discussions with each other, e.g., “Is she dying well today?” Hospice caregiver descriptions of what the good death means center their own abilities to effectively respond to the needs of the patient and the family. Thus, the good death:

... is when all of the symptoms, we have a handle on it. – *Nursing assistant*

... is when there aren't really surprises and everything sort of goes smoothly and that's the ideal – *Nursing leader*

... is a very big part of what we do here – *Registered nurse*

... means that we've done our job basically – *Registered nurse*

... means the patients are comfortable, that they're not suffering needlessly...and the person's in, has a sense of, of being in a good space, and having the people they need present – *Registered nurse*

The idea of the good death is crucially important to hospice caregivers in understanding the very purpose of their work. When I asked one nurse if most of the deaths that happen here are good deaths, she responded that she believed they were. She then added that:

Or else I don't think I could do it [laughs]. If it was all bad deaths, I mean palliative care, what would be the point of palliative care right? –*Nursing assistant*

Sometimes however, patients die in ways that do not fit with hospice caregiver conceptualizations of good deaths. For example,

...somebody who looks scared, and they're gasping for air, and they're just kind of hanging on, but they're dying, they're trying to hang on but they are dying. And they die like, not looking comfortable – *Nursing assistant*

The prototypical “bad death” from hospice caregivers’ perspective is someone who dies short of breath or who dies bleeding, and is aware of this as they die. When this happens, hospice caregivers might interpret this as a personal failure. While hospice caregivers report that a great number of deaths that happen here do go well, it is the ones that do not that they remember most. One of the hospice caregivers invoked the notion of a broken promise to describe a situation in which patients die short of breath.

...it's when they've begged you not to happen, 'Please don't let me choke.' And they're choking. –*Nursing assistant*

Throughout the interviews with hospice caregivers, it became evident that they are actively involved in coming to terms with death experiences that do not go well from their perspective. They struggle to accept the limits of their own abilities to alleviate the suffering of others.

...not that all deaths can be totally smooth. I maybe, I kind of have come to a point of being less anxious, and realizing that I cannot always make everything entirely smooth or perfect. I kind of, by necessity you almost have to come to a place, to terms with that – *Registered nurse*

...this took me some time but I think you have to realize that you cannot help everybody as well as you would like to... so you do your best, with the knowledge you have, but after that, it's, everybody's different...You know we are not, we are not all powerful. –*Physician*

In their accounts of what a good death means, hospice caregivers were explicit about their role in providing for patient and family wellbeing, while at the same time acknowledged that a certain degree of suffering may be inherent to the human experience of death and dying and therefore beyond their control. In the following excerpt from an interview with a nurse, this tension is apparent. She explains that in

this context, her role in providing for a good death is to provide for a “relative” sense of calm, peace, and tranquility.

David: ... what does a good death mean to you?

Wow. Okay. Um, I was going to say many things. I think first and foremost, um, no suffering.

David: Um hmm.

Whether that be physical or emotional. Spiritual, whatever you want to call it. Um, I've seen many people suffer. Really suffer. Whether that be, that they, they're in physical pain. You know, they're fighting for their breath. Shortness of breath. Uh, agitation. Wanting to go home, or wanting to be somewhere but where they are. Um, or suffering in another way. Suffering saying goodbye to someone.

David: Um hmm.

You know, someone who is more consciously aware of what's going on and, the struggle. So I think that's it. I don't know whether I've answered that or not David.

David: So you've seen a lot of people suffer here?

Yeah. Yeah. Uh, I think for me, so yeah, really to get back to your, your question. If um, to have a good death would be to have a death without suffering. Now, I know it's probably, it's probably uh, what I have said maybe contradicts itself because there will always be an element of suffering...

David: Um hmm.

...possibly when you're saying goodbye to someone ... So there will be an element of suffering but I think for me, um, when I have seen so much suffering then the idea of someone having some relative calm...

David: Um hmm.

...peace, tranquility, um, then I think to me that would be a good death.

David: So is that your, in terms of your role in responding to that suffering, what is that? Is it basically to try to provide that calm and tranquility like you're saying or?

It, it's true, I mean it's, I mean there are some times, and that's a lesson that I've learned, there are some times that you can't take that suffering away. And some times that is an existential suffering, you know...it's somebody's emotions, uh whatever it be. Uh, someone once told me about uh, they need to accept this. 'I

need to accept this, that I'm dying.' But actually I don't know that people do need to accept it. It's a hard thing to accept. -Nurse

From these accounts of good death from hospice caregivers' perspectives, it appears that good death is not merely an outcome achieved by patients themselves, but also a framework that guides action in hospice caregiving. As I began to think about the good death as an action-guiding ethic in hospice throughout data collection and analysis, I became curious about the sources of influence in working toward the good death in this setting. In the next section, I describe the dimensions that appear to shape the work of hospice caregivers' toward the good death, which I call good death practice. These dimensions are: 1) Body, 2) Time, 3) Omnipresence of Death, and 4) Family

Dimensions That Influence Good Death Practice

Body.

As people die, their world shrinks. Diminishment of bodily function results in a limiting of a patient's geographical horizons, as their place-in-space narrows (Carlander et al., 2011). Perceptions of confinement can be threatening to the good death. For example, in a narrative inquiry study of stories about what makes for a good or bad death, a family member participant stated "...to be as I see my brother right now, it's a very small world...I thought that his world was the size of the hospital room...I wouldn't want that world" (De Jong & Clarke, 2009, p. 64).

In the hospice, some patients are mobile. They are able to get themselves out of bed, walk around the hospice and enjoy the kitchen and living areas. Most require some type of assistance to mobilize but again, many are well enough to sit outside on the patio, or to have breakfast in a chair in front of their television. Eventually, all patients will deteriorate to a point where they will spend all of their time in bed. Most will become less responsive until they are comatose, and they will die asleep, located in the bed.

Often, hospice caregivers come to the conclusion that it is best for patients to stay in bed *before* patients or families themselves accept this idea. A popular phrase used by hospice caregivers is that a patient is "dying on his/her feet." Hospice caregivers become concerned that mobilization places too much of a burden on the patient's

comfort and safety (i.e., fall risk) when their bodies are extremely weak. In these situations, patients and families sometimes continue to request assistance in transferring from the bed to a chair, a commode, or the bathroom. This can sometimes become a source of tension in the caregiving relationship, as described in the following fieldnote:

Right as I come in this morning, a nurse asks me if I have met Ms. I. She says that yesterday was “painful” (she uses this word many times as she tells this story). She describes that Ms. I is “dying on her feet” and that her mother is “fixating,” always “at” her daughter. Ms. I was standing near the window, wide stance, arms outstretched, and exclaimed to her mother: “You’re smothering me!!” Ms. I’s mother was trying to get the patient out of bed to go to the bathroom, which was troubling for the nurse as the patient is so weak. The nurse tells me she told the patient (firmly) “I can’t drag you to the bathroom, you’re going to have to stand.” She did stand and was able to go to the bathroom, but the nurse says the whole process took half an hour and repeatedly says, “it was painful.” The nurse relays that Ms. I’s mother told her that her husband was moving right up until the moment of his death, and she reasons that Ms. I’s mother wants this for her daughter as well, to “keep her moving until she dies.” The nurse says she was really “on the verge of losing my patience” but also says that “if it were my daughter,” she would probably be acting the same way. –*Fieldnotes*

The day after I wrote this fieldnote, this nurse sat down with me for a recorded interview. We talked about the idea that hospice caregivers struggle in finding a balance between tailoring their care in a way that acknowledges, affirms, and enables the goals that patients and families have for themselves, while at the same time ensuring the comfort and safety of the patient against a context of inevitable bodily deterioration and functional decline.

So it's trying to get that fine balance [between medicating a patient for breathlessness and maintaining their wakefulness] I think is, is tough.

David: Um hmm.

And we're always, constantly trying to find that equilibrium. It's always different.

David: It's like uh, what was the patient's name, the one who had heart disease and he was in the chair all the time?

Yes, yes, yes. That's correct, you know.

David: Because he wanted to stay awake

Yeah, that's right and he really did. And he was uncomfortable and he looked physically uncomfortable. But I remember, um realizing, that you know what, that's what he wanted to do. He wanted to sit up, and hunched over, like so [hunches over to imitate].

David: Um hmm.

And so we'd be on our knees trying to nurse him [in his chair] the best that we could.

David: Yes. [chuckles]

That I think we're very good at. That I think we're, we're good at meeting the person where they are.

David: Right.

And I think we...

David: Literally, physically...

Yeah.

David: ...down on your knees and uh...

[in unison] meeting them where they are.

And, and realizing, you know what, sure it would have been easier for me and him possibly...

David: Um hmm.

To be nursed in bed, but he didn't want that.

David: Um hmm.

And somebody said something interesting to me um, yesterday, someone's mom [the mother of Ms. I] who said, 'You can't block them from doing what they want to do.' And block was an interesting choice of words, but I understood what she meant.

David: Um hmm.

She meant that, you know, by saying, 'Well we're not going to take this person out of bed,' or, 'We're going to do this. We're going to do this.' Our agenda.

David: Um hmm.

We have to, we have to meet them where they are.

David: This is Ms. I right?

Yes, that's correct. That's correct. And you know, and I remember saying, 'Well, I want you to be aware that I'm not blocking. It may look like I'm blocking,' but...

David: Um hmm.

'But this is where I'm coming from.' You know?

David: Um hmm.

I'm coming from a safety point of view or a security point of view.

David: Um hmm.

But yet I took the time to see, was that patient able to do what she wanted to do? And she was.

David: Yeah.

She did it with a struggle, but she did it. –*Registered Nurse*

In addition to declining mobility and wakefulness, bodily changes in dying entail a loss of control over one's body boundaries (e.g., bowel and bladder function). Such control is conventionally necessary for accepted membership in civilized society, and therefore loss of this control can be threatening to notions of identity and social presentation of self (McInerney, 2007). Hospice caregiver discussions are regularly replete with references to changes in their patients' bodily features. During change of shift report, patients are described using such terms as "swollen," "sweating," "mottled," and "grey." As patients progress toward death, their bodies become unreliable. Transformations in their bodies that are observable to others expose and make visible the fact that they are dying. The following excerpt is from my interview with a volunteer who works in the hospice kitchen. She does not participate in patient care. My conversation with this volunteer helped me to understand the ways in which dying patients are seen by people whose everyday work does not involve coming into

contact with their deteriorating bodies.

Every once in a while a patient will show up [to the kitchen]. In fact there was one woman that showed up uh, she was delirious a little bit, I guess they kept giving her something and, once in a while a patient will want to go for a walk. A lot of them just stay in, most of them stay in their rooms. And, obviously thin, she was emaciated you know, I don't know what she had. And she came up to the counter where we get our food, and she was hanging over it. And her, her clothing was all like too big, and she was sort of hanging out of her clothing. And her hair was all disheveled and, I mean she looked sick. She looked like a sick person. But, I think it was her brother, cause he looked her age, had taken her out of the room and she was sort of wandering around, but she was sort of touching the food ...obviously she was having a good time. But she also was, uh, she was grabbing a little piece of cake, a little bit of this, a bit of that... But she wasn't all there cause I think of the medication.

D: How could you tell that she was not all there? Just...

Oh you could just tell.

D: Right

Yeah no, her eyes were not good and, um she was sort of pointing to certain things and took about four or five pieces of cake. Which is fine, it wasn't about that but,

D: Yeah

she obviously couldn't be eating it all. You could just tell she was treating herself. You know and,

D: Right

... but it's not like a person who's, who's in a hospital and they've had an operation and they're ready to go home and they've got their housecoat on and everything. And I think um, uh, she was just with her brother she wasn't with a nurse. So I guess he didn't know to put anything around her or, you know he was just trying to help her. I mean she wanted to get up and go for a walk. You know I think if it would have been her sister or her mother they would have gotten her to put a shawl on or something.

D: Ok

You know. But I mean there was no harm done. I'm saying this sort of thing happens once in a while. Once in a while somebody's sitting at a table and they've got their [oxygen concentrator], or a thing, and they're looking all frail. But when

they're sitting they often need help. When they come here [hospice] they're often quite frail. -*Volunteer*

In the above excerpt, this volunteer explains that hospice patients are visibly identifiable by their frailty and by the equipment that exposes their bodies as ill, e.g., an oxygen concentrator. The particular patient in this scenario “looked like a sick person.” From this volunteer’s perspective, this patient was unlike a hospital patient who has “their housecoat on” and is ready to re-enter the world of the living. Rather, this woman was dying. She is described as “not all there.” We do not know if this patient was delirious, though this volunteer appeared to think that she might have been, describing her as “delirious a little bit.” It is particularly interesting to note that this participant appears to be concerned for this woman’s dignity and is somewhat perturbed that others allowed her to *be seen* in this “emaciated” state. She supposes that if it had been another woman walking with her, as opposed to her brother who “didn’t know to put anything around her,” such a female caregiver “would have gotten her to put a shawl on or something.”

Just as the volunteer in the above example encountered death through witness of a deteriorating body, so too do images of bodily change affect how families experience their loss. For example, some families are interested in participating in the nursing care of the patient, and nurses facilitate this participation. Hospice caregivers are mindful of the impact that seeing and touching the patient’s exposed body can have on the family’s overall experience, as explained by the following excerpt from an interview with a nurse.

A lot of people will say, you know if they want to stay in the room for a bed bath, or a position change, and I’ll encourage them, okay, maybe massage them here if you’d like. Or maybe wash their back.

David: Um hmm.

And then almost everybody will say, ‘Oh! They’ve lost so much weight.’ ‘Oh [exasperated sigh], look at the leg. The leg is like the arm now.’ And that kind of thing. So it’s loss. It’s loss of the person that they knew. -*Registered Nurse*

In this setting, aesthetics are important for the good death. Some of the bed linens are colourful, and some of the nurses are particular about which gown will look

best on a particular patient. When patients die, a colourful quilt is laid over their body before it is wheeled out of the hospice. In dying however, patients' bodies sometimes change in ways that are disturbing to the aesthetic dimension of dying well. For example, respiratory congestion in an unconscious patient close to death sometimes produces a loud, gurgling noise. This congestion can sometimes be very difficult to treat with medication and is threatening to the idea of a good death because it disrupts the image of the patient gently slipping away. Various body fluids, including urine, feces, vomit, and blood, regularly escape dying patients' bodies and create a messiness, visual and olfactory, that contrasts sharply with the beautiful environment of the hospice space. Lawton (1998) observed a similar disconnect in her ethnography of hospice, which she described as the *unboundedness* of the dying body. She suggested that the falling apart of patients' bodies in dying was threatening to their sense of self. In this hospice, I similarly observed hospice caregivers to infer a sense of suffering for their unbounded patients as resulting from processes of physical and mental change. In the following example, a nurse grieves for a patient who was previously the embodiment of dignity and grace, but whose current abject embodiment (Waskul & van der Riet, 2002) is threatening to his good death from her perspective.

I ask the nursing leader, "how is W?" He's not good, not doing well. She says he's confused and aware he's confused. He was crawling out of bed this morning. Apparently this is new – has not been going on before. She goes on to say that he has lost even more weight, that he has a new fistula, and that he was vomiting fecal matter. "He's not having a good death" she says. I ask if he's very distressed by all of this. She thinks so – based on what she's been reading in the chart. She says that throughout his stay he has handled everything with "such dignity and grace" but now she thinks he's finding this very difficult. -*Fieldnotes*

Part of hospice caregivers' commitment to promoting bodily integrity and body aesthetics in dying is enacted through establishing a care environment that does not use many of the medical technologies that are found in hospital. There is a general anti-technology attitude here that is consistent with hospice caregivers' goal of creating a home-like environment. Intra-venous pumps, blood pressure cuffs, and thermometers are all signs of hospitalization, and from the perspective of hospice caregivers, risk alienating the body from the self (Wilde, 1999). The cultural attitude of hospice caregivers toward medical technology in dying is similar to what Johnson et al (2000)

found in their study of EOLC in the intensive care unit. In that environment, the attitude toward advanced technology in dying was that:

A death without “machines,” “tubes,” and “lines” is considered both more dignified and aesthetically pleasing. The body, encumbered by “ugly,” noisy, and invasive equipment transfigures the patient into a cyborg of sorts, making his or her humanity and biological self less recognizable.” (p. 284)

Similarly, the following excerpt from my fieldnotes shows how medical technology can threaten the idea of a good death from hospice caregivers’ perspective:

During team rounds, a new patient is discussed who arrived yesterday from internal medicine at a downtown hospital. The patient had 3 intravenous (IV) lines, a nasogastric (NG) tube, and an oxygen mask. The team laments that “it was troubling to see her yesterday” and that this appeared to them “a very medical way to treat someone who’s dying” One team member exclaims “Shame!” All of these technologies have since been removed, and someone remarks that, “you wouldn’t have known she was the same lady.” The psychologist points out that she has learned that the family now plans to bring the grandchildren in to say goodbye, which they weren’t planning to in hospital.

Later in the evening, I go into this room. The patient is sleeping peacefully, skin clean, hair done, with nasal prongs for oxygen delivery. The nurses and patient care attendant are all talking about how different she looks; one of the nurses keeps saying, “She’s beautiful.” One of the other nurses says that yesterday, with all the IVs, NG, and oxygen mask, “you couldn’t even see her.”

The nursing leader then goes into the room, saying she wants to see this patient. She emerges from the room with a big smile and gives her colleagues a “thumbs-up.” -*Fieldnotes*

Despite the generally sceptical attitude in this setting toward technologies such as those mentioned above, the good hospice death is, nevertheless, technologically supported. Technologies that regularly interface with patients’ bodies in this setting include nasal prongs and tubing for oxygen delivery, urinary Foley catheters, and syringe drivers. Nasal prongs deliver a small concentration of oxygen (less than five liters per minute) to the patient. Because this is the only mechanism of oxygen delivery used here, patients need to require less than five liters per minute to be admitted. When oxygen concentrators are used, they create a loud humming noise that can be heard outside of the patient’s room. Foley catheters consist of a soft plastic tube placed

inside the bladder to collect urine that drains into a clear bag that is secured to the side of the bed. Syringe drivers contain various medications for pain, nausea, delirium, and/or anxiety, and are attached to the patient via a long plastic tubing and small needle to allow continuous subcutaneous delivery. The rationale for employing each of these three technologies is to preserve and foster embodied wellbeing in dying. Oxygen and the medications delivered through syringe driver effectively target delirium and shortness of breath. The syringe driver is the primary mechanism to ensure round-the-clock delivery of pain medications. The Foley catheter takes away the burden of having to get out of bed to urinate. It also restores *boundedness* in an incontinent patient, potentially protecting his or her dignity (Lawton, 1998). Thus, it is not technology *per se* that is anathema to the good death, but rather the meanings attributed to various medical technologies (Seymour, 2001) that dictate their role in either supporting or preventing a good death from hospice caregiver perspectives.

Time.

Ideally, the dying process is gradual and incremental while not prolonged. Hospice caregivers feel that a certain amount of time is necessary for patients and families to fully benefit from the services that are offered. The hospice hopes to provide patients and families a place in which they are given some time to create their own good death, e.g., to put their affairs in order, to revel in each other's company, to say goodbye. Recall from Chapter 1 that the hospice philosophy is about "maximizing the potential the patient and family still have for activity, relationship, and reconciliation" (Saunders, 2000, p. 11). Further, as admission to the hospice is "overwhelming" for patients and families, they require time to settle in, become comfortable, and establish trustful relationships with hospice caregivers. Time is therefore necessary for caregivers to build therapeutic relationships with patients and families and to feel that they have made a positive difference in their end-of-life experience.

For these reasons, deaths that happen too soon can undermine good death practice. Although the admission criteria specify patients who are expected to die within three months, many patients are admitted much closer to death. Half of the patients will die within five days of admission, and the average length of stay is less than two weeks. The relatively short nature of most admissions and the rapid turnover

of patients take a toll on hospice caregivers. They often lament the busyness of their work in terms of the great number of deaths that occur in a short time. A physician once commented during a particularly busy period that she feels like she is working in a “mouir,” a pejorative French term to describe a place where people are brought just to die.

The following excerpt is from my interview with the hospice psychologist. A large part of her role is to provide counselling to patients and families while they are in the hospice, offering emotional support as well as anticipatory guidance as they prepare for death. She is also very involved in coordinating the provision of bereavement support to families throughout the one-year period following patient death. In our interview, she spoke in detail about how short admissions *complicate* good death practice. This happens when the length of stay is insufficient for hospice caregivers to provide patients and families with the support and guidance that they are felt to need.

David: Is there, are there situations where deaths don't go well?

Oh absolutely.

David: Where in the final analysis you would look back and say that was a bad death?

I wouldn't use the word bad actually... But complicated grief when it's sudden. Um, we have had just a case or two where a person has a CVA [cerebrovascular accident] or a stroke or something ... and it's sudden, whether it's on the commode, or they're sitting in the recliner, and one minute they're talking, and so in that way it's not a bad death, but it's a complicated death because the patient thought and the family thought they had all this time...

D: Ok

...to finish...Um, those are tough. Those are not what I would call good deaths because they're sudden, which means complicated grief because no one said goodbye.

D: Uh huh

It's similar to a trauma death. That you're working with the family and trying to get resolution, and they didn't get that time. So we have those. And we also have the admissions from the hospital, our record is five minutes.

D: Right

You know, and they're gone.

D: Like in the door and then they're dead?

Yeah, yeah. An hour, two hours, twelve hours, we get a lot of twelve to twenty-four hours. You don't have time as a psychologist, social worker, to get all the team educated for one thing. We all read the charts constantly to see each other's notes but um, to get us all as a team supporting this family, and this patient. And talking about what's going to benefit this patient as they're dying and leaving us, and beginning their journey and all those, those enriching ways. When it's that short you can't do it.

D: Uh huh

So, in that case then, the doctor and the nurse make them as comfortable as possible. We don't get much time with the family till after, and our bereavement program then kicks in with our support groups, our support callers... *—Psychologist*

From this excerpt, it appears that short admissions complicate good death practice in at least two different situations. First, death sometimes happens unannounced. While most patients in hospice follow a somewhat predictable course of decline toward death, they are so ill at this stage of their illness that death at any moment is possible. When this happens, despite having been admitted to hospice for EOLC, the death is interpreted as "sudden" and is therefore traumatic, robbing patients and families of quality time together before death. Second, good death practice is made more difficult when patients are admitted so close to death from hospital or home that hospice caregivers do not feel they have enough time to provide optimal care and support. In these situations there is no time for the team to come together and learn from each other what the most important issues are with this individual patient and family, and how best they should be responding. In these situations, the "doctor and nurse make them as comfortable as possible," but there is no time to enact a whole-person care approach that is so central to hospice philosophy.

Time is important for the development of trusting relationships. When nurses and patient-families do not have time to become familiar with one another, difficulties are

more likely to develop in their relationship (Macdonald, 2007). In this hospice, all of the admitted patients will, sooner or later, deteriorate and die. Many families are unfamiliar with the dying process, and therefore hospice caregivers are extremely vigilant in guiding them to see the changes and eventual death of the patient as a result of underlying illness, and not as a result of palliative interventions or hospice admission. This is a particular challenge when the length of stay at the hospice is short. In speaking with the volunteers who offer support calls to families in bereavement, for example, they mentioned that family members will sometimes express ambivalence about the hospice experience, where *He was fine, then we brought him to hospice, and then he died*. In the following excerpt, a nurse expands on this concern.

D: So what's a bad death?

A bad death. Well for me it, bad deaths as you put it, happen when the patient isn't admitted early enough to palliative care. So we get them towards the end of, you know the dying process often, and we don't have time to get their symptoms controlled. And then if they die very quickly, then it's just a nightmare with the family. Because you know you're giving medication to try and alleviate, often, terminal agitation, so the family sees this going on, and they're you know unsure of what's caused the death. You know like they'll, they're nervous about medication. They're, they don't understand what's going on, I just find it's really difficult. And we haven't had that many for awhile, but every once in a while we'll get a...

D: That many cases like that?

Cases where they'll come in and the patient dies within 8 hours, 12 hours, 24 hours, and I find those are really difficult. The patients are usually not well controlled, and the families are a mess because they're so in shock at the speed of what's happened. I find that's really difficult.

D: And you mentioned developing trust with the families as an important element of everything going well...

We don't have time to do that. Yeah we don't have time. –*Registered nurse*

Interestingly, while hospice caregivers spoke about short admissions complicating their ability to facilitate good deaths, this does not automatically imply that patients should be admitted sooner to hospice. At times during fieldwork, when I noticed that several beds were empty, I would ask the nursing leader about whether

there were currently any patients waiting to be admitted. The answer was often that there were indeed patients currently at home who qualified for admission, but when called and offered a bed they would decline, saying they were “not ready yet.” Hospice caregivers affirmed this choice. They spoke repeatedly with me about how their own visions of what it means to die well include staying in the setting in which patients are most happy and comfortable for as long as possible.

Despite the challenges imposed by short admissions, the good death is still possible within a narrow time frame. In the following example from my fieldnotes, I listen as nurses talk about a patient who died forty-five minutes after being admitted.

I arrive at the hospice at 3 pm. There is a body in room #6 – she came from hospital this afternoon at 12:30 pm and died 45 minutes later. A daughter will be coming in later, and the family might require support and a “quicker follow-up” as there was a sudden change: last night the patient was confused but talking, and she then deteriorated very suddenly. The patient was 81 years old, “but they (family) say she is a young 81. She was a dancer, both her and her husband were professional dancers.”

The nurses talk about how fast it was. Someone asks if this was the shortest admission ever – someone else answers that no, it was not.

The nursing leader remarks that the MD wrote “the admission note and the death note at the same time!”

I then speak with the nurse who had been following the patient at the hospital⁴. I ask her if it was good for the patient to have come. She actually pushed the patient over here from the hospital across the parking lot in a stretcher – and this made the family happy. They told her they were glad she got to experience being outside. The nurse smiles as she tells me this.

This nurse thought the patient would live longer, “I thought she had a day in her,” and she was quite surprised that she died so fast. She spontaneously admitted to questioning whether her or the hospice’s actions contributed to her death: the stress of the transfer, and the fact that her 100% oxygen via face mask was decreased to five liters, which is the maximum here.

I ask whether, even if the transfer did contribute to the death, is it still a good thing that she came here? The nurse reasons that yes, it is. She reports that when the patient’s condition very suddenly changed last night, all medications

⁴ Two of the nurses who work at the hospice also work as palliative care liaison nurses at the community hospital. This work is paid for by the hospice and is meant to provide better continuity of care for patients between hospital and hospice contexts.

by mouth were discontinued including long-acting narcotics. These were not replaced with anything subcutaneous, as the doctor there felt that the sudden change in status could have been due to drug toxicity. The nurse rolls her eyes at this idea. She characterizes the hospital physician as “refusing to see” that the patient was dying, and we talk about how the patient appears to have been “abandoned” by the medical team where she was. -*Fieldnotes*

In this example, good death practice involves: 1) coming to know something personal about the patient and family, i.e., that she and her husband are dancers, 2) going to great lengths to ensure an imminently dying patient is given a chance for a comfortable death, i.e., pushing her across the parking lot in a stretcher, and 3) providing for optimal pain and symptom management, i.e., switching her oral pain medication to subcutaneous delivery and framing this as protecting the patient from medical abandonment in dying. In these ways, good death practice, even in the context of short admissions, is an approach to care that is much more involved than merely providing patients with a place to die. It is in ways such as these that hospice caregivers find meaning in their work, despite the occasional feeling that one is working in a *mouroir*.

While short admissions complicate good death practice as described above, so too do lengthy admissions. Officially, patients are appropriate for admission if they have an expected life expectancy of less than three months. In practice however, hospice caregivers start to raise questions when the patient doesn't die or seem to be dying soon after several weeks of admission. On very rare occasions, a patient might be transferred out of hospice and back into long term care. Although some hospice caregivers express ambivalence about this practice, there is largely a group consensus that when a patient is not benefiting from the type of care that this place is designed to offer, i.e., EOLC, the bed would be better used by someone else. Three months is a long time to “block” a bed from being accessed by other potential patients who may need it more urgently. When beds are occupied for lengthy periods of time, the wait list for admission into the hospice grows, and patients die before they can be admitted.

Taking a long time to die also undermines good death practice because it is a source of shared suffering amongst families and hospice caregivers. Patients who are “actively dying,” i.e., unconscious, body deteriorating, death anticipated at any moment,

for longer than a day or two are referred to as “lingering.” Once hospice caregivers have done all they can do to facilitate a good death, lingering threatens to undo this work.

Even though you’ve done everything you can do and, and they, you know, they’ve done everything they can do. And they may have said everything they need to say, but still the person’s lingering, lingering, lingering. –*Registered nurse*

Lingering in a state close to death appears threatening to notions of personhood, identity, and preserving integrity in shaping the good death from the perspective of hospice caregivers and sometimes family. When this happens, the patient’s death is awaited with explicit eagerness.

In the nursing station I can hear very loud breathing. I ask the nurse if that’s Mr. R I hear. She goes to the room (I stayed behind). When she returns she says that she turned him over onto his side, which helped. She goes on to say that his wife said to her “he would hate this.” I ask her if his wife is finding it long. She replies that she is. “She said he was lingering, she used that word.” - *Fieldnotes*

I’m sitting at the desk at 3:30 pm, waiting for report to start. The three nurses are busy charting, and then somebody mentions Mrs. O in room #4:

Nursing assistant: “She’s gotta go soon.”

Registered nurse: “She doesn’t look good, she looks scary, it’s scary for the family.”

Nursing assistant: “Oh she’s gotta go, this is ridiculous.” –*Fieldnotes*

Lingering is also threatening to the family’s good death. As patients linger, families may infer patient suffering by sheer virtue of the fact they are still alive though appear lifeless. There seems to be something fundamentally undignified about this situation, regardless of how comfortable or peaceful the patient seems.

I chatted with a nursing assistant in the nursing station about Mr. B and his family. She says, “It’s long for them eh? There’s nothing we can do for that. They just have to wait” [i.e., waiting for death]. –*Fieldnotes*

Further, as patients linger families become exhausted. Families might also become preoccupied with other worries such as having to return to work or needing to know when they will be able to return home to a different province or country. Concerns such as these appear to inform the assessment of long dying as lingering.

Lingering may, however, also serve a function toward the good death. The label of 'lingering' allows the actual death event, when it does come, to be perceived as a release, thereby conferring positive meaning to the fact that the patient is now dead, as in the following example.

This morning at 7:30 am, the nurses coming on shift realize that a patient they knew in #6 died yesterday. They are initially taken aback, and then:

"Well good for her"

"The last few days were not good"

"She needed to die" -*Fieldnotes*

Further, a patient who "lingers" in a state of perceived comfort for some time may buffer painful memories of previous discomfort. In my conversation with one family member, the daughter of a patient who was felt by hospice nurses to be "lingering," she talked about how her father had been delirious and agitated a few nights prior to our conversation. This experience was very disturbing to her and her family. When I asked for her ideas around what it might mean for her father to experience a good death, she emphasized themes of peacefulness. I asked if, from her perspective, her father was dying peacefully now, and she said that he was. It was therefore interesting to consider that if her father had died immediately after becoming agitated, this may have resulted in a greater threat to her image and memory of a peaceful death for her father than she currently held, as a result of his now "lingering" state.

Omnipresence of death.

In many ways, good death practice is about creating a care environment that is more about living than about dying. In documents that are made public about the hospice, e.g., media communications, caregivers describe that this is not a place to die but rather a place to celebrate life. Indeed, the food, the sunlight, the garden, the music, and the joyful attitude of the staff and volunteers all contribute to a life affirming vibe that is certainly felt here. Simultaneously, however, signs of death permeate and are quite visible. In every patient room, a poem is mounted on the wall that contains the words: "We will be with you in your living and in your dying" (Figure 3). In the nursing station, there is a posted note instructing which physician to call "when a death occurs." When patients are admitted they or their family member sign a consent form that

states that they understand that the care here is focused on “end of life.” Death certificates are sometimes partially filled out before the patient dies, so that once the patient does die the only things left to record are the date, time, and physician’s signature. Signs of death are visible in other types of documentation as well, for example scraps of paper found on the desk in the nursing station containing information about patient preferences for cremation and funeral home choice. The turnover here is rapid, patients die on a daily basis. An empty room that has not yet been cleaned and made ready for the next admission is a stark reminder that someone has just died here.

Previous ethnographic studies of large-scale and acute care environments show death and dying to be hidden experiences that lurk in the shadows of ward culture. Kaufman (1998) demonstrates that much of the difficulty of dying in acute care has to do with the ambivalence and ambiguity that surround decision-making and goals of care as patients deteriorate and die in these contexts. Costello (2001) reveals a prevailing practice of nondisclosure of terminal diagnosis to patients and families, which he interprets through reference to Glaser and Strauss’s (1965) notion of closed awareness:

...an examination of hospital ward culture, including interpersonal power relations, beliefs about nurse patient relationships and the protective strategies used to keep patients in the dark about their terminal diagnosis, reveals the existence of a number of tacit agreements. These unspoken rules appear designed to maintain a conspiracy of silence pivoted on compliance with medical instructions about nondisclosure of the truth to dying patients. (Costello, p.65)

In contrast to medical environments such as these where impending death is obscured and denied, hospice gives rise to a counterculture in which ideas of openness and acceptance of death predominate. In the following excerpt from my interview with the hospice psychologist, she speaks to hospice caregiving practices that are directed at “getting (family) on that page” i.e., a place of shared and open acknowledgement of dying and impending death. Such strategies include combining written and verbal explanations, as well as proffering conceptualizations about death that are demystifying and reassuring.

Families sometimes have a harder time. We had a lady ... who wanted to put tape over the sign, because she didn't want her daughter to know she was going into palliative care. So, sometimes it's the family who's in denial, and so getting them on that page, sometimes our printed information helps, we have a lot of booklets for the kids, grandkids. Uh, to explain death and dying to the different ages of development. Uh, so the printed materials will help. Um, talking about the D word [death] which nobody ever talks about, the elephant in the room.

D: yeah

And we say dying and death, and things like journey ... we use the death word and that helps the family, as hard as it can be on them to use that word, it helps them get on the page with us, to say ok we're moving toward death, we know that much. We don't know how long, we never predict the day or the, how long, but, ... we do get the family to be able to use that word death and to realize that this is your goodbye time. And that this cycle of life's just as important as the beginning. - *Psychologist*

Death and dying are everywhere within the walls of this hospice; at any given moment patients fall into one of the following three conceptual categories: 1) *Dying* - admitted to the hospice for EOLC and currently progressing toward eventual death; 2) *Actively dying* - death is expected at any moment; and 3) *Dead*. A very small number of patients can be considered to occupy a fourth conceptual category: *Not yet dying*. These patients do not belong in hospice as they are not seen to benefit from the type of care provided, and so discharge out of the setting is usually discussed, and sometimes accomplished⁵.

Patients and family members are openly encouraged to acknowledge and talk about death in this setting. That everyone is here for the same reason, to die, makes it easier to plan and deliver care that is specifically focused on meeting EOLC needs.

...people are scared in the hospital. People are petrified. And especially when they don't know what's going on with them. Here at least people know one thing. They know that they're dying." -*Nursing assistant*

⁵ During the period that I conducted my fieldwork, the hospice was a single nine-bed facility as described throughout this thesis. Since that time, however, the hospice has expanded its program and now provides in-patient palliative care at a nearby location, where the admission criteria do not require patients to be as close to death. These beds will be used for patients who are dying but perhaps not as imminently as the patients described in this project. They will also offer admissions for purposes of family respite.

Patients engage with the imminence of their own death in unique ways. Some speak of waiting to die, hoping that the process will not be drawn out for too long, while others continue to appreciate the little time they have left, as in the following contrasting examples of two different patients.

Mr J:

I asked him how he is doing. He is physically comfortable and as for the setting and the care he “could not ask for better.” He seems content enough, or at least is presenting himself that way, but he continues to seem bored. He watches sports on television, though has never really liked television. He has meals and gets washed. He doesn’t have the concentration to read. In response to my questioning, he says he still feels the same as he did last week: He is anxious to die as soon as possible. *-Fieldnotes*

Mr R:

Right after report with the MD, the nurse mentions that R will need someone to sit with him if he’s to go out and have his cigarette, and she seems concerned that she does not have time for this right now. I suggest that I can do that. I sit with the patient outside on the patio. It is a glorious day, hot and sunny, while he smokes two cigarettes. I ask him what matters most to him at this stage, and he says, “Being alive!” He talks about being afraid to die, but that when he mentioned this to the MD he was told that everyone, this MD included, is scared to die, and he says he found this reassuring. He says that the idea of death is scary because it is unknown, no one has ever come back to say how it is, but that his morale is good and he feels great. He says he is taking things day by day, and gesturing to the trees in front of us he remarks, “It’s beautiful here!” *-Fieldnotes*

Some family members actively anticipate the patient’s death, sometimes with eagerness and sometimes with trepidation. Other family members resist acknowledgement that the patient is dying. Hospice caregivers interpret that this resistance means that further work around acknowledging dying and death is probably required:

...let’s say denial, you know like right now a family for instance... It’s a big family and there’s one family member who looks to be, like her attitude, I think she’s in denial. ‘Oh my father’s strong, he’ll get over that,’ you know? I know it’s her way to cope, you know it’s her way of coping but, but trying to sit with her, if she allows me obviously, and trying to understand where she’s at, and try to explain to her also exactly what she’s seeing as her father, what do we see now. And make her accept or realize or admit that her dad’s condition’s has deteriorated. He’s no longer responsive. You know try to make her accept the fact that dad is very sick and um, hope for recovery or improvement is essentially nil. *-Social worker*

Family.

Hospice caregivers and family both hold as their primary and fundamental concern, at this time and in this place, the best interest and wellbeing of the dying patient. Despite this common goal however, each can have different, and sometimes oppositional, ideas about what this means and/or how best to achieve it. When hospice caregivers or family do not share the other's values, approaches, or opinions about what the patient needs, they are set up for a tenuous relationship that can complicate good death practice.

It is a little frustrating to watch someone suffer. It's more frustrating to watch when we're not convinced that it's the patient who's making the decision, that it's the family making the decisions. I think that aspect is what [we] have more trouble with. –*Nursing leader*

The road to the good death is smooth when families and hospice caregivers share an overall assessment that the patient is comfortable, is dying well, and that the care strategies and clinical management are appropriate. This requires hospice caregivers and families to trust each other and to position themselves as allies, with each showing faith in the other's efforts to achieve what is best for the patient. The extent to which families are prepared for the patient to deteriorate and eventually die, and the extent to which they are accepting of hospice caregiver interventions and medications administered, represents the degree to which they are "on board" with the hospice ethos. Engaging with families involves guiding them to understand and appreciate what is at stake:

Sometimes it's really hard for them to grasp what's the important thing here. –
Registered nurse

When families are not on board, the stage is set for a more complicated or difficult death.

David: Is the family that accepts, does that go better? Is it a better death?

Definitely. I've seen good deaths where family members start wailing and crying and jumping on their loved ones at time of death because they just, weren't, they weren't ready for that one to, their loved one to die.

David: Sorry you said those were good deaths?

The good death for the patient, but not for the family member.

David: Ok, so everything went well and then at that moment, then it not so well...

It collapsed. Everything collapsed. So I think supporting the family, supporting the family members, preparing them, educating them, um, um, bringing them to reality, sometimes it's just they're in denial, even though they're in palliative care and this facility is for end-of-life care, they may not really be psychologically ready for their loved ones to pass away, so it's basically making sure that they're on that page that they should be on. – *Registered nurse*

The goals of family members may conflict, at least initially, with the goals of hospice caregivers. Having perhaps been socialized into a medical system that emphasizes treating and fixing, families here are re-socialized toward accepting and embracing the priorities of hospice.

They have to know what [our hospice] is all about. It's not a rehab clinic. Ok? It's not a place where you're here to gather your strength and go back home...it's a place where you'll die with dignity. Okay? That's getting on board. A lot of patients are fearful of that, okay, so they're brought here under false pretenses. 'Oh you're just here to rest Daddy. You'll be fine!' You know that's not true. And you're caught in the dichotomy as a doctor, as a nurse who works here, to make the people understand that that's not what this place is about. - *Physician*

The priorities of hospice are invariably directed toward promoting patient comfort, minimizing patient distress, and facilitating quality relational connection and interaction between patients and their intimate others. Further, because dying is accepted as a normal process here, part of the socialization into the hospice way of life entails an acceptance that certain interventions that may have seemed appropriate in previous circumstances are not appropriate now. Part of helping families to understand what palliative care means is to explain, "we don't do that here." This is generally regarding life-prolonging interventions that might make the patient uncomfortable or that might unduly medicalize the dying process, e.g., trying to feed a patient that does not seem interested in food, drawing bloods, initiating intravenous hydration:

That's one of the things you start working on right away with the family, the minute they walk in the door. Explaining how things work here and what we

do here. And the family might say, 'Well I think he's dehydrated. Did you, should start an IV or something?' And then maybe we go into the whole explanation of the palliative care, that we don't do that here. For various reasons. We're not prolonging things here. Be careful with your choice of words of course. This patient is, your father is dying. And um, it's not gonna help him to hydrate him, and his body probably can't, his body can't handle the hydration anyways because everything is breaking down. –*Registered nurse*

Letting go.

Everyone admitted to the hospice is here for the same general purpose: to receive EOLC. Dying is what unites the patients and families with the hospice caregivers, it is because of dying that they have come together in this specific place at this particular time. Unlike in a hospital, where nurses may be caring for patients with a wide variety of issues and prognoses during any given day, the singular emphasis on end-of-life caregiving in this setting enables a concentrated and focused attention to the dying process and the intricate details of what dying does to patients and families, physically, psychologically, socially, and spiritually. Although entering hospice to begin with would seem to convey some degree of acknowledgement, if not acceptance, of impending death, family members are seen to require much guidance in coming to terms with impending death. A large part of the focused attention in hospice on the dying process then, is helping family members to *let go*. This includes letting go of ideas of cure or illness reversal, letting go of wanting the patient to eat, drink, or get out of bed, letting go of previous patterns of relating to the patient, and eventually letting go of the patient him or herself. This focus on letting go is reflected in the words and phrases hospice caregivers choose when speaking with families, as in the following example:

A patient was admitted to the hospice and apparently the family was very concerned that the patient was not eating. One nurse tells us that she explained, in one of her first conversations with them, "He's not dying because he's not eating, he's not eating because he's dying." The other nurses are impressed with these words, and one says she's going to "use that" in future. –*Fieldnotes*

According to a grounded theory study that explored the determinants of quality EOLC from the perspective of hospital nurses, "creating a haven for safe passage" is an overarching theme of quality EOLC (Thompson, McClement, & Daeninck, 2006, p. 93). According to these authors, death denial is an obstacle to the facilitation of an optimal

EOLC experience. Conversely, when care providers, patients, and families all clearly understand that the patient is dying, the transition to EOLC happens “swiftly and smoothly” (p. 95). Hebert et al. (2006) suggest that being prepared for the impending death of a loved one predicts better psychological adjustment to the loss. These authors assert that preparedness, defined as “the degree to which a [family] caregiver is ready for the death” (p.1165), is dependent on the quality of communication between family members and health care professionals. Lowey (2008) suggests the following defining attributes that describe letting go of a dying loved one before death: shifting one’s thinking, recognizing impending death, acknowledging physical and emotional loss, and allowing inevitable death to occur without impeding its natural progression. According to Lowey’s analysis, family members need to understand that letting go of their dying loved one is in the patient’s best interest. She suggests the consequences of letting go as follows:

As a result of letting go, the movement of life can go on freely, without guilt that wrong decisions were made. After letting go, the individual is freed of an emotional weight of unrest and turmoil, and healing and growth can begin to take place. After letting go, an individual can release their loved one and experience peace. (p. 212)

In this hospice, helping families to let go is an important part of working toward the good death. While this is done to help families with their own adjustment, there is also a prevailing belief that patients will have a better death when their family gives them permission to die.

We [psychologist and social worker] work together, and make sure that the family is on board, on the same page as the whole team, uh, giving this person the opportunity to say their goodbyes, have permission to go, let go, get permission from the family sometimes that’s important. Um, a quote would be, ‘I want you to know Dad that I’m letting you go, it’s ok to go now, it’s ok to die.’ - *Psychologist*

I think it helps the patients also that we focus a lot on families and making sure that they understand everything that’s going on. The whole process, making sure that they’re comfortable, and it makes like an easier transition for the patient to just let go, because they see their family being less anxious. Most of the time I find unless there’s like a special case it’s all about acceptance, you know, and then they sort of leave more peacefully that way. -*Patient care attendant*

One of the most noticeable instances of hospice caregivers' engagement with families toward acknowledging and preparing for the patient's eventual death is their practice of encouraging families to make arrangements with a funeral home before the patient dies⁶:

David: I've noticed that there's a lot of arranging with the funeral homes, sometimes before patients die, and sometimes families are guided through that process of making arrangements with the funeral home. Do you have any opinions on that or sense of, like, what sort of a priority is that?

Well, I find that prearrangement is probably the best thing for family members so that those issues are not, those issues are taken care of. Because if someone dies, and they don't know which funeral to deal with they have that stress to make those arrangements at that time. When to bring up that topic is another issue. If a patient all of a sudden starts changing, and you start to say well it's time to do a pre-arrangement, um, that might not be the best time. It probably was a week earlier, if not more than that. Um, because their energy should be spent with their family members if that's what their desire is to be, with the family member. So I think pre-arrangements should almost be like a requirement when they come in here. *–Registered nurse*

Summary

The work of hospice caregiving is directed toward creating good deaths for patients and families. In this sense, the good death is a patient and family experience as well as an action-guiding ethic that orients and guides the practice of hospice caregivers. The good death means hospice caregivers have a handle on distressing symptoms so that patients and families can experience a peaceful end of life transition as a result of hospice intervention. I found good death practice to be shaped by the four dimensions of body, time, omnipresence of death, and family. Hospice caregivers tend to patients whose bodies are disintegrating. They attempt to foster dignity through a largely technology-free space, while at the same time make use of selective medical technologies that promote embodied wellbeing in dying. Patients' bodies deteriorate

⁶ While this practice is about facilitating letting go, it is simultaneously about protecting family members from negotiating funeral costs when they are at their most vulnerable, i.e., immediately after the patient dies. Also, there is no morgue at the hospice. When a patient dies, it is the funeral home that will come to collect the body directly. Thus, prearrangement prevents family members from having to make a decision as to which funeral home to use in the immediate moments following patient death.

within a context of narrowing space. As they weaken they become confined to their rooms and invariably die in their beds. Ideally, death does not happen too soon after admission so that a relationship among caregivers, patients and families based on trust and collaboration has time to develop. Equally important however is that death does not happen too long after deterioration toward death has significantly undermined the patient's identity and social presence. When this happens the patient is seen to be lingering, a threatening phenomenon in which hospice caregivers and family are suspended together in a liminal space between life and death. While the hospice is at once a dynamic and lively space in which life is celebrated, death and dying are omnipresent.

The good death practice of hospice caregivers is facilitated when families are on board with the goals and priorities of hospice. Conversely, the good death is complicated when families are not on the same page as hospice caregivers with respect to what is most at stake at this stage of the patient's illness. Hospice caregiving practice, then, involves helping families to come on board with hospice philosophy. This means letting go of previously held ideas about the appropriateness of medical interventions, e.g., intravenous hydration, letting go of one's position as caregiver toward embracing instead a role as client, and letting go of the patient himself or herself.

Read together, Chapters 4 and 5 respond to the first research objective, *Articulate an emic perspective of hospice caregiving culture to interpret the practice of nurses and other caregivers in their facilitation of good deaths for terminally ill patients and their families*. While delirium was not the main focus of analysis in these two chapters, the examples used thus far to illustrate the overall context of hospice caregiving do show that delirium is a potentially important issue in this setting, e.g., the reflection of the kitchen volunteer about the (possibly) delirious patient who "looked like a sick person," the woman who died after only forty-five minutes in hospice, having suddenly become confused the previous night in hospital, and the wife of a dying patient who said she could not "live through" another night like the last, during which her husband was delirious and agitated. Now, the analytic focus narrows to look specifically at the relationship between delirium and good death practice. The second objective of this research study is to: *Articulate an understanding of how working toward the good death*

in hospice caregiving practice influences and is influenced by the conceptualization, assessment, and management of end-of-life delirium. This objective is the focus of the remaining findings chapters.

Chapter 6: Conceptualizing Delirium

Introduction

At the inception of this research study, the initial guiding questions were about delirium and its significance concerning the ability to facilitate good deaths in palliative care. Over the evolving course of fieldwork, I found I needed to temporarily suspend these questions in favour of a more basic curiosity: What is delirium? Although this is a question for which an answer already exists in professional health literature (see Chapter 2), attention to how this question might be answered in the context of this setting, for these caregivers at this time and in this place, became important. This was because my understanding of ‘What is delirium?’ as already proffered through conventional medical and nursing conceptualizations increasingly seemed to me somewhat asynchronous from the daily practices and routines, the daily realities, of hospice caregiving.

One example of such asynchrony is the tendency of hospice caregivers to infer purpose underlying delirious behaviour. While a psychiatric diagnosis of delirium requires the symptoms to be attributable to an organic cause, hospice caregivers sometimes infer a personal meaning behind the agitation and restlessness that they witness in delirious patients who are very close to death. This is reflected in the language that they use to describe these experiences. In the following example, a nurse invokes a notion of a patient resisting and “fighting” her own death:

The patient wanted to get up but she was so weak. The nurse says that she was fighting until the end. She thinks she knew she was deteriorating and that she was fighting this. She would scream for help to get up, where “part of it was delirium.” -*Fieldnotes*

Further, while patients’ delirious communication would often seem unintelligible and patients would be described as “not making sense,” the images evoked by them would sometimes seem meaningful given their current situation of dying. For example, one delirious patient referred to her hospice nurse as “the reaper,” had hallucinations of people dressed in black, and in response to being told by her nurse that her daughters would be in to see her soon, replied, “There will be nothing left.” Other times, when patients became delirious, hospice caregivers would integrate their understandings of

delirious manifestations with prior knowledge of the patient and family's relational history, as in the following example:

Team rounds discussion of Ms. V:

On the weekend she was in delirium, and slapped her daughter. This made the daughter very upset. The psychologist says, "So she's dying like she lived, in conflict." -*Fieldnotes*

Another curiosity that emerged from my reading of the delirium literature and subsequent fieldwork in this setting concerned the variable use of the word "delirium" in hospice caregiver language. When patients would be described as "confused," "out of it," "agitated," "restless," or "hallucinating," the word "delirium" was sometimes used and other times not. I could not discern any consistent pattern to this variability. This did not appear to simply be a situation of some patients satisfying diagnostic criteria while others did not. The clinical approach to all of these patients, with respect to pharmacological and non-pharmacological delirium management, seemed uniform. Thus, I began to ask myself questions about the relevance of the actual delirium label to hospice caregiving practice. I hypothesized that care of patients who exhibit symptoms typically understood to indicate delirium depends less on clinical reasoning through a specific diagnostic lens (i.e., DSM Delirium) than through a more basic engagement with the thought processes, communications, behaviours, and reactions of the patient in order to determine what they are experiencing, whether they are suffering, and what needs to be done to help them. This certainly seemed to be the case when towards the end of my fieldwork, I listened to the team discuss a particular patient during morning report with the physician. The team engaged in a lengthy discussion of the patient's dysfunctional mental state. He was described as "manic," "hyper," oscillating between periods of "calm" and "agitation." His sleep-wake cycle was perturbed. The group wondered as to his own "conscious awareness," and lamented about how unfortunate this situation was for him, "it must be terrible," and for them, he was very "demanding." I carefully listened to hear if the word delirium would be used in this discussion and it was not. Discussion then turned to whether they should rotate his opioid regimen (i.e., switch him from fentanyl to morphine). They could use a syringe driver, but would he pull it out? Perhaps they should give him regularly scheduled doses every four hours?

The physician mentioned adding midazolam (a sedative hypnotic) to be given regularly four times a day, and one of the nurses affirmed this suggestion, “something to just chill him out.” Another nurse said that previously she was concerned about making him sleep, but now she was no longer ambivalent, as “he’s suffering.” When I was sure the discussion was over and the team was ready to move on to the next patient, I interrupted and asked, “So is he delirious?” The group pondered this for a moment, and then decided that yes, he was.

In considering the question “What is delirium here?” during data collection and analysis, it became possible to clarify how hospice caregivers in this setting conceptualize end-of-life delirium. Attention to how caregivers in practice conceive of various health and illness phenomena is important as such conceptualizations affect interactions within the caregiving relationship (Rhynas, 2010). Manifestations of cognitive disturbance are extremely common in this setting. As patients die they are expected to weaken physically and mentally. Thus, signs and symptoms of delirium that invariably represent pathology in care contexts outside of hospice are in fact normal here. For these caregivers, delirium does not, by itself, hold any universal significance within conceptions of good or bad dying. What is most important is not whether a patient “has delirium,” but whether he or she is mentally suffering. Mental suffering is a broader conceptual category than delirium and refers to patients who are perceived to not feel safe in their own space. They are:

“...wanting to be somewhere but where they are.” –*Registered nurse*

Conversely, mental wellbeing is an inferred sense of peace and comfort, cognitively and emotionally. From the perspective of hospice caregivers, mental wellbeing is determinant of the good death whereby:

“...the person’s in, has a sense of being in a good space.” – *Registered nurse*

In this chapter, I describe mental suffering and mental wellbeing as organizing constructs that orient and direct hospice caregivers toward promoting psychological, social, and spiritual wellness so that patients can have a good death. It is my observation that, in this setting, all of the work that happens around delirium, i.e., assessment, diagnosis, monitoring, palliation, is subsumed within and cannot be teased apart from these broader conceptual frames of reference.

Mind-Body Dualism: Delirium as Embodied Experience

In suggesting the concepts of mental suffering and mental wellbeing as lenses through which the delirium experience is interpreted by hospice caregivers, I need to outline here what is meant by *mental* in this context.

In their descriptions of good deaths as dying without suffering, hospice caregivers regularly and consistently differentiated between suffering that is rooted in physical discomfort and suffering that is attributable to some other non-physical source, as in the following two examples:

A good death I think, in this environment, is one which the patient's at ease, um, that they're not suffering, whether that suffering is physical or emotional.
Registered nurse

David: What does the idea of a good death mean?

...to have the patient well controlled in his pain. But I would say total pain, as much as the physical is the, probably the first thing we look, emotional pain is also very important. –*Nursing assistant*

Nursing literature and theory has devoted considerable attention to questions of mind-body relatedness. Often attributed to Descartes' philosophy, nurse scholars are generally agreed that the conceptual isolation of mind from body is an antiquated notion, an ontological fallacy that denies an integrated and embodied idea of human beings. According to Paley (2002), 'Cartesian dualism' is problematic for nursing because of its potential for a dehumanizing practice that reduces the body to biology and abstracts it away from other qualities that are inherent to personhood. Paley writes, "As with positivism, Cartesianism is now known to be a Bad Thing. It represents an easy and uncontroversial target, so criticizing it is safe (and guarantees an appreciative audience)" (p.189). While the conceptual integration of mind and body may be widely accepted in theoretical discourse, however, in the everyday talk of hospice caregivers it is common to hear references to mind-body distinctions that might be interpreted as "Cartesian":

David: Do you find that most of the deaths that happen here would satisfy that...

That idea of the good death? I would say so. Some more than others...But as far

as the physical body, it's definitely taken care of here. –*Patient care attendant*

There is an order to this conceptual division of suffering into physical and non-physical dimensions. For hospice caregivers, alleviation of “physical pain” is primary, i.e., happens first. The belief that suffering due to physical discomfort is needless and antithetical to receiving good palliative care guides hospice caregivers in their ordering and prioritizing of assessments and interventions. In the following example, a nurse explains that when faced with a patient who appears to be suffering, her first priority will be to ensure adequate pain relief *before* moving on to consider delirium as a potential source of the patient's discomfort.

...a new patient has come from the hospital and they're thrashing around in the bed. They're not able to communicate what's going on with them, they seem to be totally out of it, they don't respond to you verbally, they don't respond to anything. But even if their eyes are open, but even so, you know they're uncomfortable, and there's something going on, and they can't tell you there's something going on. Um, you try the pain route first. And if you find that that doesn't seem to do anything, then you might look at delirium. –*Registered nurse*

The alleviation of physical discomfort is a goal in itself, however it is also a means toward subsequent engagement with other domains that influence wellbeing in dying:

...sometimes when you get, when you look after the pain, the physical pain, and the physical discomfort and symptoms, then the patient is kind of faced head on with dealing with emotional issues...Because when you take away the physical pain...and then if there's issues in their family or in their past or whatever. Or they have existential issues, they're afraid of dying or whatever, so that kind of comes to the fore. If everything else is cleared up. So then you have to deal with that sometimes. –*Registered nurse*

While the idea of humans as embodied beings who are physical-psychological-social-spiritual all-at-once is recognized in this setting, it nonetheless seems necessary in practice for hospice caregivers to tease apart, for their own purposes, these various aspects of personhood and experience. One reason for this might be the idea that physical suffering is easier to respond to than mental suffering. When patients are not physically comfortable, there are clearly established clinical management protocols in place. Through the administration of medications and basic nursing care, most patients can become physically comfortable.

Symptom management to be honest with you is a challenge, but it's not

overwhelming. Once you kind of see what works for the patient, you keep them on that, maybe tinker a little bit, but because they're [caregivers] so good, they got that under control. –*Nursing leader*

Mental suffering is more elusive than physical suffering and creates greater difficulty to hospice caregivers in their orchestration of good deaths. Hospice caregivers do not have easy solutions for what they interpret as “emotional pain.”

The emotional part is even harder to manage than the physical part. Because the physical part, the physical pain, usually the medication will help, in any event up to a certain point. The emotional pain, some people, we're not able to reach them. They will leave [die] with that disturbance inside of themselves. And it doesn't matter if you give them medication, they'll probably be just asleep, but they, they're not uh, we didn't really help them to resolve the problem. So in a way I think that's suffering, it's bad. – *Nursing assistant*

Faced with non-physical suffering, there is a significant emphasis on listening and being available to patients and families, as they work through their own issues and confront their own death experiences.

A lot of times it's just a question of sitting with the patient or family members and listening to their concerns, uh, that's our role here. – *Volunteer*

...usually it's just exploring, letting the person talk, that they find their, they're gonna find their own solutions. –*Registered nurse*

David: What sort of role do you play for example in, like suffering that's not physical?

Um, I, presence, psychological support. I hope I'm there to decrease anxiety and answer their questions, and just be there with them. Help explore their thoughts and feelings. Um, if they just need a moment to be with someone, or if the family needs extra support, that's what I'm here for. –*Registered nurse*

Given that hospice care and providing for a good death are interprofessional team efforts, labeling elements of the patient's experience and suffering according to physical and non-physical dimensions helps to clarify which team member can be most helpful with whatever issue is at hand.

I think that there [are] several aspects of a good death. Obviously as a doctor um, I'm gonna approach it first by the medical aspect. Um, I would say that a good death medically means that a patient's symptoms are well controlled, or optimally controlled. –*Physician*

...we review with the patient, mostly with the family, the list of physical things that are gonna occur as one dies, in the body systems, what's going on there, our nursing staff does that. Psychologically, I work with the families on helping them understand what it means to let go, what kinds of things they can talk about, um, what's helpful to the patient. - *Psychologist*

When it comes to medical questions, I'll refer them back to the medical team because that's not my...

D: Area?

That's not my area. - *Volunteer pastoral care provider*

Moreover, different team members will set their own priorities for assessment and intervention based on their own unique focus and position within the team.

Although the patient's delirium was discussed during the meeting with the son, the psychologist tells me it was not the priority. She says that during the meeting, the physician's priority was to discuss the patient's pain control, and to agree with the patient's son to start a syringe driver. Her priority as a psychologist was to address that the patient and her son have not yet said their goodbyes. - *Fieldnotes*

Conceptual separation followed by conceptual reintegration of human experience and suffering along physical, psychological, social, and spiritual dimensions is consistent with the professional discourse of palliative care (e.g., Ferris et al, 2002). These practices underpin the "total pain" model that is a foundational tenet of palliative care wisdom. According to Whelton (2008), these various dimensions of personhood and experience can be thought of separately, but "they are so intertwined in the living thing that it is impossible to have one without the other" (p. 79-80). This idea approximates well the ideas of mind-body that hospice caregivers hold in this setting. For example, team discussions are often rich with hypotheses about how a particular patient's bodily deterioration, which in extreme cases might be described as "rotting from the inside," is lived emotionally and relationally by the patient and family. Hospice caregivers are careful to note and attend to the psychological, social, and spiritual implications that arise, for example, when patients are no longer able to walk or eat.

In dying, rifts between physical and social identity are sometimes observed, and this can be threatening to hospice caregiver ideas of providing for a good death. In a reflective memoir about her first year of hospital nursing, Brown (2010) writes the

following about the first death that she experienced as a new oncology nurse:

When I walked into Mary's room two weeks later at the start of day shift, I did not recognize her. The breathing mask covered half her face, but more than that, the imminence of her own death had taken away some essential part of who she was. This happens: a person's body reaches a critical point beyond which she cannot be saved or even helped, and the individual's humanity recedes as her physicality takes over. Death is the final stage in that process, since in death the person's body remains, but her spirit, or soul, the force that animated her and made her who she was, is gone forever. Perhaps if our bodies vanished when we died, death would be easier; part of the puzzlement of death is that the body stays, but the person we knew and loved will never come back. (p. 32)

Brown conceives of her patient's humanity as separating from her physicality. This seems to be a common observation amongst hospice caregivers who work with dying patients in this setting. Hospice caregivers will sometimes examine the photograph on the patient's medical insurance card (found in the chart), taking a moment to reflect on what the patient looked like before terminal illness transformed them into the appearance they have come to know. In Brown's description, her patient was unrecognizable to her. This is a moral consequence to the perceived uncoupling of a patient's physical and social self. When this happens, hospice caregivers might express their opinion that it is time for the patient to die:

Change of shift report, evening to night, Mr. M:

Evening nurse: "Terminal agitation", arguing with his wife, saying he wanted to get up to urinate – got more frustrated. Agitated – scared – doesn't want to be left alone – "sees himself changing." [She clarifies to the others that what she means is that he sees himself changing cognitively]. His colostomy exploded – pooled on the floor.

Night nurse: He had a bad day.

Other night nurse: He's dying on his feet.

Evening nurse continues: Short of breath X 2. I thought he was going to die right then and there. His breathing became very shallow. Stomach becoming mottled.

Night nurse: It's time.

Evening nurse: The patient care attendant "caught him getting out of bed twice." Gave Lorazepam [a benzodiazepine] at 10 pm. Wife given written information. Wife did not want to stay the night. He's just not letting go – He's gonna fight.

After report and the evening nurses had left, I asked the night nurse if she would be surprised if Mr. M died. She replied, "No. I wish he would, poor man." –

Fieldnotes

Even in the context of perceived bodily and/or mental disintegration and expressed eagerness for the patient to die, hospice caregivers nevertheless continue to affirm and nurture the patient's personhood and are confirming of his or her social identity throughout the hospice stay.

I follow the nurses on their first evening round. In room #9, one of the nurses speaks to the patient, who is unconscious / unresponsive. She tells her, "I wish you a peaceful journey. I hope you're back on your country farm". She then tells us, "That's what she loved". The nurses talk about how this patient used to live on a country farm, where she would grow her own vegetables. -*Fieldnotes*

At the time of this observation, I noted in my fieldnotes that this seemed to be an interesting example of "seeing the person who is there." This patient had previously been delirious, and during team rounds earlier that afternoon, her dying had been described as "lingering, lingering, lingering" and "long"; one of the nurses remarked "oh, she has to die!" According to the psychologist, this patient's daughter had expressed a feeling that "mom has already died". I noted in my fieldnotes that:

While there is consensus, even hope, amongst staff and apparently family that the patient will / should die soon, in this nursing interaction the nurse keeps the person alive, showing reverence and respect for her lived life now embodied in the almost lifeless body in the bed. -*Fieldnotes*

This excerpt illustrates my evolving understanding of how hospice caregivers can at once observe rifts between bodily and social identity, interpreted as an erosion of quality of living, while still recognize an inherent dignity and personal integrity in all patients through to the last moment of their lives.

Delirium is interpreted and responded to by hospice caregivers as an *embodied experience*. This means that hospice caregivers attend all at once to the implications of the delirium experience for physical and mental wellbeing. Patients who are delirious are potentially upset, scared, anxious, paranoid, confused, or angry, and therefore are mentally suffering and experiencing "emotional pain." At the same time, hospice caregivers attend to the potential physical and bodily causes of such mental unrest, e.g., urinary retention, pain, shortness of breath. Further, patients who are not well cognitively or emotionally are seen to experience their distress *through* their bodies. The most typical illustration of this is the delirious patient who is restless and does not

stop moving. In this situation “agitation” signifies mental unrest and is displayed through bodily movement such as “crawling out of bed.”

Based on the observations and analyses described above, I suggest that the practice of hospice caregiving in this setting is faithfully oriented toward a philosophy of whole-person care. At an ontological level, hospice caregivers recognize their patients as indivisible whole beings who are not reducible to “physical” and “mental” components. Nevertheless, these labels serve a purpose of helping hospice caregivers to discern what the priority issues are. The cultural ethos of creating a safe place for dying depends on an integrated notion of physical and mental wellbeing. Physical and mental wellbeing are for hospice caregivers two distinct conceptual categories that are overlapping and mutually interdependent. Appeal to these conceptual categories enables hospice caregivers to recognize and attend to the multidimensionality of patients’ experiences of living and dying.

Hospice Caregiver Conceptualizations of Delirium

In the following example, a nurse remembers a patient whose mental suffering was effectively palliated. Delirious and confused on admission, this patient experienced cognitive clarity prior to his death. Reversal of his delirium put him in a better “place,” where he was able to reconnect and resolve emotional issues with his family, and where hospice caregivers were able to get to know him better.

David:...the guy who was in #3...

Oh yes, yes, yes. He was a great story. Yeah.

David: Ok so tell me that story.

Well he’s the one that, climbing over the bedrails, putting his legs in the plastic bag, and uh, very, very, very, I call it lost. Like confused. And eventually with intervention, medication, everything, he became so much more clear, and I think he had a much better quality of life for a short period of time before he died. Cause he was clear, he was able to communicate, he made a lot of progress with his children.

David: Cause there had been relationships, there had been issues right?

Yeah with him and his children.

David: Yeah. So kind of, that afforded him I guess more time to...

To resolve issues.

David: Right.

And I guess, you know what he was probably in a better place when he died. That's my belief. He was probably in a better place after having that clarity. And being able to resolve those issues. When he came in he was not in a place where he could have done that.

David: In a place?

In a place like cognitively, he was not in a place, he was confused.

David: Right, so, so it's almost like the interventions to manage his delirium, contributed to a better death?

Absolutely. I believe.

David: Yeah. Because like, I remember a phrase that you used, you said 'we fixed his delirium.'

Oh really? We fixed his delirium. Yeah I guess.

David: Is that fair would you say?

Yeah like, definitely, yeah he improved. He was much more clear. He was less confused, able to communicate. I remember him slipping back into a bit of a delirium towards the end. But uh, yeah, we were able to get to know him better because he was less confused.

David: And was that largely through medications that that happened?

I believe so, for that case? I think it was, yeah medication. And all of the little interventions.

David: What sorts of interventions?

Well, the interventions like, the stability of being here, getting his family in and getting his issues resolved once he became more clear. Uh, I think everything together with the medication. I think it was probably everything that helped.

David: Great.

That was probably the clearest case, of delirium being resolved. Most probably

because it was the longest one. That's one of the patients that has been here the longest with a delirium, so, it was very clear that he came in very confused, became much clearer, then became a little confused again and then he died. – *Nursing assistant*

In this example, delirium threatened the good death because it robbed the patient of a safe place that hospice caregivers work so hard to create. He was lost. Through reversal of his delirium, he was afforded more time for quality wakefulness. His good death was enabled through pharmacological delirium management as well as “all of the little interventions” that refer to everyday practices of hospice caregiving. From the perspective of this nurse, hospice care afforded this patient the opportunity to interact meaningfully with his family, and to find a better place from which to die.

Hospice caregivers facilitate good deaths by attending to the metaphorical *place* in which delirious patients find themselves and the meaning that delirious manifestations appear to hold for patients and families. Delirium can cause mental suffering, but it can also cause mental wellbeing. In the following example, a nurse explains that the central concern is whether whatever situation of mental change the patient is exhibiting is a source of distress, or conversely a source of happiness and comfort. Questioning whether a specific instance of delirium is lived as mental suffering or wellbeing involves deciphering where the patient is “at” (place), and meeting them there.

I kind of struggle with that actually [about the importance of orienting patients to time and place] because sometimes they're really happy in their bubble, and so why do I need to tell them?

David: Right

So I don't necessarily, um, tell them you know. If, if they're believing their mother is still alive and they are comforted by that, then you know why, why should we tell them?

D: Um hmm

If, if I think it will help them cognitively to know that, that this is the time that we're in, then I'll tell them...It's kind of individual...Try to meet the person where they're at. –*Registered nurse*

Delirium as mental suffering.

When manifestations of end-of-life delirium are distressing, then patients, families, and caregivers themselves suffer. First, hospice caregivers infer suffering on behalf of the patient. In an interview with a nurse, she described delirium as when a patient appears to be “wrestling” through their experience, and while they do not clearly communicate the nature of this struggle, it is apparent that “something’s wrong.” I then asked for her opinion as to whether such a struggle at end-of-life constitutes *suffering*:

David: When somebody is delirious in the way that you’ve just described, would you say that that person is suffering?

Yes. I would say that they are agonizing subconsciously, more subconscious I think. In their unconscious state, yeah, they’re suffering. There’s something going on here that they’re not happy about. They’re not happy, that’s for sure. – *Registered nurse*

While hospice caregivers seem confident in their appraisals of distressful delirium as suffering, they were less clear with me about *how* they know this. Delirium often involves loss of cognitive access to the patient, such that delirious patients are not able to coherently explain what they are feeling. Rather, inferences of patients’ suffering in situations of delirium seem to be based on a:

“...gut feeling.” –*Nursing assistant*

Hospice caregivers interpret delirious patients as sensing that something is wrong and as feeling scared or threatened. Delirium of this type is considered a form of “emotional pain.” In the following conversation with a nurse, she tells me of her opinion that delirium as emotional pain requires an engaged response by the caregiver, to enable a good death. Interestingly, she differentiates between authentic engagement that helps the patient through delirium, and practices that merely mask signs of suffering, i.e., sedation.

I think if we did not take care of the delirium, I don’t think they’ll have an easy death. I mean maybe they will be asleep, again that’s my point of view. But I think if we’re not taking well, if we’re not taking care of the delirium, the patient will probably be more sedated. But we didn’t really work on the delirium. We didn’t really help him on his emotional pain. –*Nursing assistant*

When there is inferred suffering because of delirium, hospice caregivers feel morally compelled to respond, to “do something.” Again, the patient’s emotional distress is what underlies the moral urgency of the situation, as emphasized in the following reflection:

When I see a patient in delirium, first of all that means the patient is not well, is not comfortable, is afraid, is anxious. So, doesn’t matter he’s at risk of fall and everything, but I think the patient is not well in his mind and body...so this is the thing that I find, it’s urgent to do something for that poor patient ... So a patient in delirium, can be many many causes for that, but the patient inside is really in big distress and it’s like a pain, a physical pain really. - *Physician*

Hospice caregivers are also very concerned for family members at having to witness their loved one in delirium communicate and behave in ways that betray their underlying sense of who this person is. As described in Chapter 4, creating positive and peaceful images that will be remembered by family is a source of shared pride amongst hospice caregivers. That the last image of the dying person will instead be one of suffering with delirium, therefore, undermines the idea of providing for a good death:

It is traumatic for a family to see someone that was so different and now is so, whoa, off the wall. -*Nursing assistant*

Finally, hospice caregivers suffer themselves when their therapeutic efforts seem futile. Caring for patients whose distress from delirium resists all attempts at reassurance and comfort is frustrating and exhausting. In the following example, a nurse speaks about the distress she feels when witnessing the patient and family suffer through situations of both hypoactive and hyperactive delirium.

David: What about the impact of end of life delirium on staff?

Ah, that's interesting. From my, uh, from my own point of view, that's distressing.

David: Um hmm.

And the suffering that I spoke about before, it's distressing. It's exhausting because again, um, you're, you're trying to meet people where they are. So somebody's leaving. Somebody's saying good-bye to someone that they love. And there are many different obstacles in the way you know, um, to a smooth ride...

David: Um hmm.

...if you like. And whether it be pain or symptom control, whatever it be. We can work on that. Um, we may be able to get the pain under control. We may be able to stop the vomiting and the nausea. We may not be able to stop the, the acute end of life delirium.

David: Um hmm.

Which depending on what the presentation is, is distressing, you know?

David: Um hmm.

Hypoactive, you know, uh, withdrawn. Quiet, not wanting to talk. Not wanting to eat the nicely prepared Indian food that was just brought for them.

David: Yeah.

That kind of thing. It's a loss. It's another loss.

David: Um hmm.

Because food is love and caring is love. And, so if you're refusing to speak or interact, or on the contrary, not recognize and climb out of bed and yell and scream and swear and, and do all of those things that may not be the character of that person.

David: Um hmm.

When they were not, when they were well. Uh, that's distressing.

David: Um hmm.

That's distressing for the patients and the family, and it's distressing for us. –
Registered nurse

The restlessness and agitation associated with delirious dying can disturb the prevailing social order of peacefulness, calm, and comfort. Hospice caregivers conceive of distressful delirium as contributing toward a disquieting interval between mental wakefulness and unconsciousness; an uneasy temporal space in which patient wakefulness is of questionable quality. In addition to the implications of this for the patient's emotional experience of dying as already discussed, the work of caring for

dying patients becomes more difficult during this period.

They're pulling out foleys ... they're pulling out syringe drivers and they're climbing out of bed, so now we got a fall, we might have a fracture, which has happened, and so it is, it complicates matters. –*Nursing leader*

Patients in delirium may exhibit behaviours that are dangerous from caregivers' perspectives, and they are likely unable to connect and collaborate with hospice caregivers during their care. Therefore, when delirium entails such shared suffering, hospice caregivers eagerly wait for the next phase of the patient's trajectory, when consciousness inevitably decreases and the patient sleeps.

The nurse mentions to me Ms. H who was delirious over the weekend – now she is “dying” (unconscious)...Later, I accompany another nurse on a round, who remarks, as we're leaving the room, “It's so nice to see her like this!” (sleeping). She then goes on to explain that she had a very hard night with her on Sunday – she took off her own colostomy bag several times and put her fingers in her stoma, covering herself in stool...She later says that Sunday was one of her “hardest nights” because nothing she did helped; the medication “didn't touch her.” –*Fieldnotes*

The patient's unconsciousness will eventually result as a consequence of the dying process, however sedating medications that are given to palliate the symptoms of delirium may also contribute to a hastened state of deep sleep. This state can be bittersweet; hospice caregivers are happy when their patients no longer evidence signs of delirious suffering, though are sometimes ambivalent around their role in administering medications that result in sedation at the end of life.

...there are times when you feel I wish there was something else I could do.

David: Yeah.

Rather than giving increasing doses of something until somebody sleeps.

David: Right.

You know? And that, I think is a challenge for all of us. But it's a big challenge for me because you know, I have no fear of using medication because I know why I'm using it, but the secondary effects of sleep and not, no other waking periods, it, it's hard. It's difficult. –*Registered nurse*

Delirium as mental wellbeing.

In stark contrast to the conceptualization of delirium as suffering, hospice caregiver conceptualizations of end-of-life delirium sometimes involve interpretation of positive meaning and an overall appraisal that the experience is one of mental wellbeing. In the following example, reference is again made to the notion of a metaphorical *place* to which the patient is transported as a result of delirium.

I think for the patient, it, depending on the delusions, it can put him in a good place. You know, that it's a way that the brain has, almost like a coping mechanism, where you're getting ready for the trip. -*Psychologist*

Mental wellbeing means being in a good place, emotionally, relationally, and cognitively. From the perspective of hospice caregivers, delirium can contribute to the patient reaching that better place. This goes beyond the conventional descriptor that is prevalent within clinical practice of labeling patients as *pleasantly confused*. Rather, interpreting alterations in cognitive experience as wellness occurs through a thoughtful assessment that signs indicating delirium, e.g. disorientation, hallucinations, are beneficial to the patient's achieving a good death. My conversations with two hospice physicians, described below, each reflect such an assessment.

A new patient was admitted yesterday, Mr. T. The staff mentions that he lost his wife earlier this year. I mention to them that, "apparently he was having hallucinations of his dead wife?" as I had read this in the nursing documentation last evening, and the MD said yes. She uses the words "cute", "lovely", and "beautiful" to describe how she thinks and feels about what is happening. She says that apparently the patient was "giggling" at these hallucinations, signifying that there is no apparent distress. She is also critical of a physician at the hospital who apparently thought his hallucinations were "creepy." This is a viewpoint that she definitely does not share. -*Fieldnotes*

On my entering the nursing station, the MD says "one patient who is delirious is Mrs. C!" Apparently she sees her deceased husband sharpening skates, she thinks it's winter. The nurse says "she's not quite there." The MD says she doesn't think it's medication related, as "she's not on anything to explain that." The MD further says that the patient seems comfortable, so "I won't treat it, she's happy." -*Fieldnotes*

In considering the varied ways in which caregivers conceptualize end-of-life delirium, as suffering and as wellbeing, it is noteworthy that family members also

diversely interpret what they are witnessing as the cognitive capacities of their dying loved ones change. For example, while one patient's son told me that it was difficult for him to experience his father's cognitive deterioration as this was a man who "read books and would remember everything," another patient's daughter told me that she was grateful for her father's confusion as this signaled to her that, after a lengthy illness, he was now "really dying" and she could let him go. Yet another patient's sister described to me her view that recent cognitive changes had no effect whatsoever on her sister's social presence:

...Mme T is adamant that throughout her sister's dying process, throughout periods of agitation, throughout this phase where she is no longer talking, her sister is still present, which she describes as "conscious." She reflected that the Monday night event and other previous experiences have been labeled by staff as "delirium," "confusion," and "hallucination." She says, "Call it delirium, call it whatever you want, but she's still here. She's still conscious, and she will be until the last moment of her life." – *Fieldnotes*

Delirium as change.

That a patient's mental status will change as they die is anticipated and accepted by hospice caregivers. Often, delirious behaviour signals to hospice caregivers that the patient has transitioned from "dying" to "actively dying". Metaphors for change, such as "turning a corner," convey that alterations in consciousness and cognition are normalized as inherent to the dying process:

Change of shift report:

Day shift nurse: ...We may be heading towards a terminal delirium, I don't know, we'll know in the next few hours. Now she's sleeping – she looks comfortable. "Be aware that she may be turning a corner" Evening nurse: Sounds like it, from what you're saying. – *Fieldnotes*

As a harbinger of deterioration-toward-death, manifestations of delirium alert hospice caregivers to the possibility that the patient may become uncomfortable as death approaches, and to be on the lookout for this.

Team rounds, discussion of Mr. E :

Nurse: Syringe driver hydromorphone and midazolam, added haloperidol (an antipsychotic) today. Since this morning he has to be prompted to swallow. "Maybe a little delirium starting." Dying.

Nursing leader: He's dying comfortably?

Nurse: Well, this morning he was agitated. He wasn't in a good place. Wanting to get into a chair.

Other nurse: "Restless."

While conceptualizing delirium-as-change enables close monitoring of the patient's comfort and potential distress as death approaches, this conceptualization is also a resource to hospice caregivers in their work with families. Sharing with families the conceptualization of delirium as an anticipated change that signifies the patient is closer to death facilitates their own acknowledgement of impending death. One morning, for example, a particular patient was described to me by the doctor as "out of it" and "withdrawn", and by the nursing assistant as "changing so fast" and "confused." She would ask for the bedpan, not urinate, and then say that she urinated. Her son had been very disturbed by his mother's sudden change in mental status; he recognized that she was different by the vacant look in her eyes. His response to his mother was "Mom! Do you know who I am?" The psychologist spoke with this patient's son that morning about the "little deaths" that occur as the personality and the brain change at this terminal stage. Later, I took the following notes listening to the hospice caregivers chat about this case in the nursing station:

Apparently today is the first day that the patient's son has begun to explicitly process and reflect on his mother's dying. The team seems encouraged by this. Apparently his aunt will teach him how to cook, as he has lived with his mother and she did all the cooking. He also knows he will need to get a smaller apartment. It appears that witnessing the sudden change in his mother's mental status facilitated (or forced?) him to connect with the idea that his mother is soon dying.

This then seemed to continue over the day, where this morning he was saying to the nurse that he hopes his mom makes it for his birthday in two weeks, but later today he was standing over the bed, crying, saying "she's going to die today." This was in the nurse's presence. She told him that they will continue to tell him as they observe more "changes," that his mother won't just die suddenly. The nurse also describes to me that in this interaction, although the patient had not been "making sense" all day, that in this moment her son said "I love you Mommy" and the patient looked at him and said "I love you too." The nurse suggests that, "That was all she had to offer." –*Fieldnotes*

Recall from Chapter 5 that *time* is an important influence on hospice caregivers' abilities to facilitate a good death. Sudden deaths are traumatic; families require time to integrate loss and come to terms with the realities of their loved one's dying. In conceptualizing delirium-as-change, hospice caregivers offer to families an interpretation of the dying trajectory as incremental. Loss of usual patterns of cognition and relatedness are reframed as "little deaths," which, ultimately, are hoped to soften the burden of the final and ultimate loss, the biological death of the patient.

Distress and the paradox of cognitive awareness.

Underpinning the various conceptualizations of delirium as suffering, as wellbeing, and as change, the central concept of concern to hospice caregivers is distress. The question of distress is what mobilizes caregivers to consider whether something needs to be done to respond to manifestations of delirium (good death disturbed), or whether the situation can be left alone, though monitored, because the good death is continuing on course.

In caring for people with delirium, cognitive access to the patient's phenomenal world is limited or absent. It is harder to connect with a delirious individual to learn from them whether the situation as lived is distressing to them. One important example of such uncertainty is patients who evidence conscious unawareness. As described in Chapter 4, a cultural feature of the hospice as a safe place for dying is an ethic of open awareness of impending death. Hospice caregivers work with patients to help them come to terms with their own dying and to achieve whatever goals they may have for their end of life. In this way, conscious unawareness is a threat to good dying because it robs patients of the opportunity to reflect and to say goodbye. Effectively, it robs them of their potential to participate and engage in their own dying experience. Conversely, hospice caregivers recognize that many patients fear their own death and that many suffer emotional pain, e.g., sadness, fear, conflict, that never goes away. Further, they attend to many patients whose declining functional abilities and symptom experiences in dying are a source of suffering. For this reason, conscious unawareness as a feature of delirium in dying may serve a protective function. This idea was explored in the following interview, where a nurse and I wondered about whether in some situations

of delirium, patients might be offered a reprieve from the fear and indignity that often characterize the dying process.

... it's less dramatic. The person doesn't really know what's going on

David: Less dramatic than what?

Than somebody who's all there...Somebody who's all there knows what's going on, and probably the moments that they're not having delirium and maybe they're freaking out inside. Who knows? Maybe they're more scared.

D: you mean, people who are dying?

Yeah

D: So, if people, so people are facing their own death, and, for some, having some sort of cognitive impairment might actually kind of...

Ease it?

D: Be helpful in a certain way because they're kind of given a break from an awareness of their own dying?

I would like to think that. It's kind of what I, I mean I have no idea but, I kind of think if your cognitive abilities are, you know not there and you're kind of in la la land, well then maybe it's not as scary. I don't know.

D: Yeah. I had a patient's daughter [here] tell me that her mother was not aware that, she didn't know she was dying, and that was a good thing. Right? Like she had dementia and she had delirium on top of the dementia and this was, I mean, the agitation was a problem but the not being aware was not, from the daughter's perspective.

Yeah. Because I think of somebody who was prim and proper their whole lives, and all of a sudden they become demented or not all of a sudden but over time and delirious on top of it and are doing strange things like taking off all their clothes and whatever, peeing in the plant or in the garbage can or. I mean those are kind of inappropriate things right? Inappropriate behaviours. But if they don't know that's what they're doing, then phew! You know at least it's kind of, I mean it's, they won't be able to know, they won't be able to be ashamed of it.

D: Right

Because they didn't even know. Yeah. –*Nursing assistant*

Revisiting Delirium as a Relational Experience

As I have already described, hospice is about creating a safe place for dying through the creation of an environment that is habitable. This chapter has thus far shown that hospice caregivers conceive of delirious patients as inhabiting an alternate *place*, the important question thus becoming whether this new place is a realm of suffering or wellbeing. In this section, I revisit my conceptualization of delirium as a relational experience (Chapter 2) in order to further examine the ways in which the relationships between patients, families, and caregivers are impacted when patients are seen to inhabit an alternate cognitive *place*.

Moments of connection.

Conceiving of the cognitive changes associated with delirium as potentially producing a sense of subjective disconnectedness and emotional pain, hospice caregivers respond by helping the patient to restore his or her felt sense of connection to others. This is apparent through their attempts to reassure delirious patients through presence and accompaniment, as in the following example.

David: So what about for patients who are confused or delirious? What's it like working with those patients?

... I will sit down, take my time, try to, I know I can't rationalize but just by the voice. Maybe a bit of music... And I try, like, on the weekend there was a small incident here, with the lady in room one. And it was, we were three in the room, and I just said, no. Let, to the other two, leave. Let me just me be with her. Because you know, if there's two or three people in the room, and already they're, so just

David: Too much stimulation?

Too much stimulation I find. You know? Just. And if sometimes I, sometimes I sit, and I bring my charts, and I stay in the room. I've done that. Just with presence I find. –*Nursing assistant*

Hospice caregivers also seek to facilitate moments of connection between the patient and family in an effort to alleviate patient distress. In the following example, a nurse describes that the experience of unrest in confusion and delirium might signify a “need to make contact” with someone familiar and reassuring. The caregiving response, then, is to facilitate such contact, again toward enabling the patient to feel comfortable and

safe, i.e., to “feel more at ease.”

A good example of that is the patient who’s maybe not, a little confused, or delirium, and then there’s a loved one who lives far away. So uh, you’re thinking, well maybe they need to make contact with that person, and you know they’ll feel more at ease. And that worry or that anxiety might disappear a little bit. And talking on the phone, and even if the patient’s not apparently awake or able to converse with somebody on the phone, I mean you get the loved one on the other end of the phone talking to them, and sometimes that really makes a difference. –*Registered nurse*

Hospice caregivers are sensitive to how changes in cognition affect patients and families lived experience of relationship. Patients might express angst over feeling socially isolated despite continued presence from others. Family members might express frustration and exhaustion when trying to communicate with a delirious loved one who is not responding in a way that makes sense to them.

According to the psychologist, the patient is complaining that nobody from her church has come to visit her. This is not the case, however, the church community has maintained a sustained presence. Also, the patient is asking for the priest, though apparently is unaware that the priest has already been in to visit several times. –*Fieldnotes*

I ask the nursing assistant if Mrs. H had any family present on Sunday evening while delirious and agitated. She says that yes, her daughter was here and was very “upset.” She kept telling her mother to “stop” removing her colostomy. Eventually her daughter became so flustered, she “put on her jacket and left.” –*Fieldnotes*

Delirium therefore can interfere with the optimization of patient-family relationships during the very little time that is remaining before the patient will die. This is a concern for hospice caregivers, who see a very large part of their role as creating a place whereby patients and families can be together in meaningful and healthy ways prior to death. The impact of delirium on the relational experiences of patient and family happens through changes in usual patterns of interaction. In delirium, the ability to demonstrate love through simple and familiar gestures can be thwarted, as in the following two examples:

A patient died after less than 2 days. In the note concerning bereavement support, “Uncertain” is circled for whether there should be a quick follow-up, because:

“pt’s wife had difficulty with how pt was combative + aggressive with her during last few days awake. She wanted to hug and kiss him but this proved difficult at times” -*Fieldnotes*

Mr. B said that his father is “better” now, after hospice caregivers treated his father for agitation, which he explains by saying that now you can hold his hand without feeling like he’s going to break your thumb” -*Fieldnotes*

When hospice caregivers are not able to connect with patients due to cognitive disturbance, this can also create tension in the caregiving relationship. For example, a delirious patient may interpret a nurse’s smile as a malicious instead of a caring gesture. A delirious patient may feel that the actions of hospice caregivers are deliberately harmful. In the following example, a nurse recalls caring for a patient who was both in terrible pain and experiencing delirium. The interaction she describes in this example occurred in the context of a dressing change.

...my communication with him on his first evening here was, ‘You’re hurting me you’re hurting me, you just want to hurt me more.’ You know he wasn’t able to listen. And he wasn’t able to process anything anybody was saying... -*Registered nurse*

Just as cognitive disturbance can result in patients becoming mistrustful of their caregivers, the reverse also happens. When patients show evidence of confusion, they are sometimes considered by hospice caregivers to be less trustworthy. For example, patients who are confused are not “reliable” to report to caregivers whether they have had a bowel movement, or to call for assistance when they need to get out of bed. They are sometimes judged as trying to “compensate” or “hide” their confusion. Once delirium becomes part of an individual patient’s personal biography of dying, hospice caregivers are primed to observe for and expect it. For example, the report board will contain notes for the next shift such as “no agitation noted” for particular patients who have a history of showing manifestations of agitated delirium.

On the report board (clipboard kept on the desk in nursing station), I looked back through the notes of Mr. R. It is very interesting to note the progression of different terms used to connote his mental state. In the first box, written in red ink (that describes information received about him prior to his admission from

hospital) it says “poor insight / judgement” (September 18 - admit day⁷). In the next box (Day shift, Sep 18), the word “lucid” is written by the nurse who admitted the patient here. Then,

Sep 19, Night: “Disoriented”

Sep 20, Night: “Confused” + “Impulsive”

Sep 20, Evening: “Confused”

Sep 21, Day: “Pleasantly confused”

Sep 21, Evening: “Pleasantly confused”

Sep 23, Night: “Awake early at 4:30am - roaming in room”

Sep 23, Day: “++ Agitated and hyper in AM. New order of Nozinan for agitation if Haldol does not work”

Sep 23, Evening: “Disoriented to place”

Sep 24, Night: “Agitated - Nozinan X1, Haldol X1”

Sep 24, Evening: “Agitation”

Sep 26, Night: “Anxious”

Sep 26, Day: “Agitated early in AM, Regular Nozinan”

Sep 26, Evening: “No agitation”

Sep 27, Night: “Nervous ++” “Lost”

Sep 27, Day: “No agitation noted” “↓ nervous”

Sep 28, Evening: “No agitation”

Sep 29, Night: “Haldol for hiccups + agitation”

Sep 30, Night: “Slept!”

I confirm with the nursing leader that the underlining and exclamation point for “slept” is an expression of enthusiasm by the nurse that he actually slept, as he never does. –*Fieldnotes*

Patients who are cognitively impaired also increase the busyness and step up the pace of hospice caregiving. They may become “ringer happy” and “call every fifteen minutes.” Agitation can disrupt the calm and tranquility that is paramount to creating the overall atmosphere of hospice as a setting of comfort and safety. For example, the nurses were quite concerned one day when a new patient and family in an adjacent room overheard an agitated patient’s screams. One nurse described to me that, upon hearing these screams, the new patient and family looked at her as if to ask, “What did we sign up for?”

Alienation in the caregiver-patient relationship can also result when someone’s delirium appears to cause him or her to interact with hospice caregivers in an abrasive way. For example a particular patient, whose delirium seemed to magnify her already

⁷ In this example, I have changed the month of year to protect confidentiality.

strong personality, was humorously referred to as “my friend” and “tough little cookie” by hospice caregivers. During team rounds, the group would laugh at stories of this patient angrily throwing objects onto the floor or commenting rudely about a particular nurse’s physical appearance. According to the nursing notes about this patient, she was “more cooperative” and “pleasant” when she was medicated with antipsychotics and benzodiazepines.

Manifestations of delirium also interfere with the ability of hospice caregivers to engage directly with family members to help them prepare for death and respond to their needs. In the following two examples, manifestations of restless and agitated delirium get in the way of organizing bereavement support and offering commendations. Thus, the work of nursing the family toward their good death is interrupted:

The day shift nurse tells the evening nurses that the family has not yet filled in the bereavement support form: “This morning it was agitation, and we were not talking about death. This afternoon we have been talking about death, but it wasn’t the right time for the support form” -*Fieldnotes*

The nurse talks about how “fragile” Mrs. C is (wife of the patient). She seems to be very apologetic for not being able to manage the patient at home, and the nurse says she commended her for having done an “amazing” job. I asked her if Mrs. C seems to be accepting of these commendations, and she said maybe, but she is so “distracted” because Mr. C (the patient) is “flapping around like a shark caught in a fishnet”. The nurse uses the word “awful” to describe the experience of Mr. C’s agitation. -*Fieldnotes*

Despite the relational challenges that delirium imposes, hospice caregivers persevere in their attempts to connect, even if just for the moment, with the patient.

I was going to say you’re not developing like a relationship because the person is not all there, but then in another way I feel that you are developing a relationship, you’re just at the moment. At that moment you have a relationship with that person. And try to, you know just reassuring, a lot of reassuring, and even if they’re not making sense or whatever, kind of, kind of just go along with it in a way and not argue and not try and prove to the person that no, no, no, you’re wrong. – *Nursing assistant*

Providing care from an ethic of connection, while difficult, encourages a recognition of the personhood and lived experience of the suffering patient, as I learned one day over lunch with one of the nurses:

What is striking to me in our conversation about Mr. C's delirious agitation is the nurse's continuous efforts to "find that moment of connection" with her patient, even as his restlessness persists. She states that continually trying to connect with the person that is there is so important. She says, "This is a husband, a father." She says that, "Yes I'm tired," and, "Yes I'm eating late." But caring for this patient and this family today the way she did was a moral obligation that she could not turn away from. *-Fieldnotes*

Efforts by hospice caregivers to recognize end-of-life delirium as a moral experience, and therefore to demonstrate care and compassion in their caregiving, do not go unnoticed by family:

She (wife of Mr. D) did spontaneously talk about relationships with staff, that she has had bad experiences in the past with caregivers [elsewhere] who were "not nice," whereas here everyone has been "very nice." She gave an example where in hospital, if Mr. D was moving around in bed (i.e., agitated) and she was there at his side, the nurse was "ok with that." Whereas here, if he's agitated, even if Mrs. D is there to supervise, the nurse is *not* ok with that. Rather, they respond to the agitation, "they care," because Mr. D's comfort is a priority. *-Fieldnotes*

Restlessness and agitation.

Restlessness and agitation are cardinal signs of mental suffering in a dying patient. As potent indicators of discomfort, restlessness and agitation are visible, demand attention, and render the relational space around the dying patient uninhabitable. As Lawton (2000) observed in her ethnography of hospice dying, the good death requires docile bodies within communal spaces. Patients who are agitated and restless move incessantly, and this movement is disturbing to hospice caregivers and to families who interpret this movement as suffering. These situations force hospice caregivers and family members to acknowledge that dying is not currently peaceful, and to devise a management plan that will restore habitability and moral coherence.

I think for families, I think it's so important for those symptoms to be controlled, because it's really distressing to watch your mom or your brother or whomever try and crawl out of bed. And you know moaning and uh, seeing things, and things like that. *-Registered nurse*

In one particular case, a patient was restless, paranoid, scared, and these manifestations were a source of shared distress for hospice caregivers and for family.

Perceptions of the patient as mentally suffering affected how caregivers interacted with her. For example one morning her nurse purposefully did not perform hygiene care because in her reasoning, any sort of stimulation risked perpetuating her restlessness and agitation. The relative degree to which this patient was or was not “quiet” became a key topic of team discussions around her case. In speaking with me moments after her mother’s death, the daughter of this patient framed the relative absence of “movement” at the very end as an evaluative indicator of her mother’s good death:

I stood and shook her hand, offering my condolences. “What can you do?” she replies. She says it was expected, that’s what they were here for. I ask her, “Did it go okay at the end?” “Oh yes” she says. There was “just a little movement,” but she affirms that it was peaceful, emphasizing “the way it should be.” *-Fieldnotes*

Restlessness and agitation often manifest as a struggle by the patient to get out of bed. Disoriented, confused, and too weak to sit up or stand, these patients are variously described as “climbing” or “crawling” out of bed. This struggle is oppositional to the image of peaceful and dignified dying that is created when patients rest quietly in bed. Hospice caregivers are motivated to keep these patients in bed in part out of concern for safety, where if they get up on their own it is almost certain that they will fall.

I say: “So it seems that trying to get out of bed has been an issue for a few people over the past week” “Oh yes!” the patient care attendant replies, “especially with Mrs. V.” She describes that “every 20 minutes” she would find Mrs. V with legs and arms through the side rails, saying that she wanted to “go for a walk.” The patient care attendant tried “as gently as possible” to tell Mrs. V that her legs wouldn’t be able to handle that, but she’s not sure she understood. She tells me it was “in one ear and out the other.” *-Fieldnotes*

The phenomenon of patients “climbing out of bed” does something important to the patient-caregiver relationship. Generally, hospice is about trying to respond, within reasonable constraint, to any and every patient need. It is about tailoring care such that individual patients’ wishes and desires can be fulfilled. When delirious patients attempt to remove themselves from their bed, however, the hospice caregiver is thrust into a role of monitoring and policing. Patients are restrained in various ways, whether through bumper pads placed on the bed rails, through abdominal belts that secure the patient’s body to the bed, or through pharmacological sedation. In situations of restlessness and agitation, families appreciate that hospice caregivers take over and do

not require them to become complicit in strategies directed at keeping the patient in bed, which might cause alienation in their own relationships with the patient, as in the following example.

Mrs. H's daughter mentions to me that the nurse was "great" when her mother was wanting to get out of bed. The nurse held onto her mother to keep her in bed, which freed Mrs. H's daughter to "talk her through it." Mrs. H's daughter did not want to be the one to have to physically restrain her mother from getting out of bed. She was explicit about this action not being appropriate to their relationship as mother-daughter: 'It's your mother, you don't want to be the one to have to hold her down.' -*Fieldnotes*

Caring for a restless, agitated patient is exhausting and frustrating, according to hospice caregivers. It is a situation in which, "You can't do anything!" These patients are "inconsolable" and often do not respond to attempts at connection and reassurance. Because restlessness and agitation can signify that the patient is transitioning from "dying" to "actively dying," the situation is an urgent one; patient and family are suffering and there is not much time remaining for new "images" to be created such that the death will be interpreted through a lens of positive meaning. In such situations, pharmacological sedation is employed to restore a sense of peacefulness, to keep the patient "calm":

So there's two ranges of medications that we'll play with, depending on if the patient is agitated let's say, ok, and he's risking falling out of bed and breaking a hip, and the Haloperidols of this world are not controlling his symptoms, I will definitely go to a more sedative properties of medications to at least put him to sleep. Keep him calm. -*Physician*

Too much stimulation.

As previously described, the ethos of hospice is about creating a safe place for the good death. To this end, hospice caregivers perceive an important role for themselves in regulating the space within which dying patients and their families find themselves. They are very protective of this space as they strive to promote a peaceful, tranquil, restful, and relaxing environment for their patients. This is especially true as patients progress toward death, as their mental states become particularly sensitive to the effects of stimulation by others. Some patients are seen by hospice caregivers to do better with visitors in the room. For example, a particular patient with a diagnosis of

delirium superimposed on dementia was successfully “distracted” when her son was in the room with her, according to her nurse. Many patients however are seen to exhibit worsening symptoms as a result of the presence of certain family members. This is generally judged to happen when family members are continually “at” the patient, placing demands on them either to interact or to perform certain tasks, e.g., to eat or to get out of bed. Thus, when patients show manifestations of delirium, or to prevent patients from becoming restless or agitated, hospice caregivers step in to lessen the burden of stimulation placed by family and to provide for the patient an environment that is conducive to calm. This practice illustrates a tension that hospice caregivers face in attempting to provide patient and family centered care. While they strive to provide to families a personal space in which their privacy and autonomy over that space will be respected, they also limit families’ control over this space when needed to provide for the patient’s rest and comfort.

David: Do you ever feel, when people are agitated or delirious or restless, that you have a role to play in managing the level of, either stimulation in the room or...

Oh yes, yeah big time. Yeah that’s another area that I didn’t think of, but it’s very true. Sometimes we get patients who become agitated and we know it’s a direct result of the family members in the room with the patient. Sometimes they would have ten people in the room. There’s too much going on in the room and you can see, because you’ve been looking after this patient all day, and by two o’clock in the afternoon this patient has become really agitated. And they don’t, they might not have an issue of pain so you know it’s not the pain, it’s uh, there’s too much going on in here. And we have to intervene when it comes down to something like that. –*Registered nurse*

Such intervention can take different forms. The care that the nurse provides over the course of her shift, e.g., the bed bath, may be organized as a deliberate intervention to provide the patient with “a break” from the family.

Sometimes you know, just a nice little break with the bed bath is what they [patients] need.

David: Ok, a break, what do you mean?

A break from the family! [laughs]

David: Yeah, ok.

Just kind of say, 'We need to do care now, can you excuse us?'

David: Ok. So how do you figure out, what people need, like in those sorts of situations?

For the patients you mean? Assessing them, see how they're feeling. Usually if you see a patient's becoming tired, or they're becoming more, I want to say cranky but, becoming more agitated. Sometimes it's a sign that they need a little bit of less stimulation.

D: Less stimulation, like a bit of a break?

A bit of a break, maybe people not always after them, especially families. –
Nursing assistant

Alternatively, creating the calm felt to be important for the good death can be achieved by offering to families alternative ways of being present to their loved one. This minimizes the burden of overstimulation, without undermining families' need to be present and in relational contact with the dying patient. In the following interview, a nurse describes that while she believes she has an important role to play in "creating calmness," she does this by affirming families' desire for meaningful interaction and offering them ways to achieve this, rather than emphasizing what *not* to do.

Nights is considered when people start to rest. But there are those times, when if you walk in to a room, like on first rounds at midnight, and the lights are all on high. And the families are patting and stroking the patient, and trying to talk to them, and definitely stimulating them, and it's, yes having to create that calmness effect and calming environment is, can be an issue. And I think it's a very sensitive issue. Telling someone that you know, you have to decrease your stimulation... I tend to, instead of saying, instead of having you stroking them, your loved one's, you know just slip your hand underneath and hold them. You don't have to move, just, they know that you're there, and sit in silence with them. And that's basically what I try to give, gear towards. Instead of saying by touching, stimulating them constantly you're agitating them, you're causing them to become more distress. Try to gear it towards, in another fashion, I try to give them other ways of being there. –*Registered nurse*

Interestingly, hospice caregivers sometimes intervene in the other direction, in an effort to help family members achieve a break from the delirious patient. For example, one such patient would telephone his wife at home very early every morning and

demand that she come to see him. This became draining for his wife. Mornings were her time for respite; it was in the morning that she did the laundry, took care of other household tasks, and prepared for the afternoons to be spent with her husband. Upon realizing that this patient's telephone calls were disturbing to his wife, hospice caregivers implemented a plan, in collaboration with this patient's wife, whereby his telephone was disconnected and his cell phone removed each night. This practice then became integrated into the nursing care plan, where each evening the nurse would document that the phone had indeed been turned off for the night.

Summary

This chapter has reviewed the various ways in which delirium is conceptualized in the hospice setting. Delirium is seen by hospice caregivers to be an embodied experience of mental suffering or mental wellbeing, where these interpretations are informed by observations of patients' consciousness, cognition, emotions, and relationships. Mental suffering and mental wellbeing appear to be organizing constructs that orient and direct hospice caregivers in their facilitation of good deaths. The central question is whether a patient or family is distressed. Distress demands response, as it undermines the experience of inhabiting a safe place as death approaches.

In this chapter I have also revisited the conceptualization of delirium as a relational experience and offered certain hypotheses as to the impact that manifestations of delirium have on patient, family, and hospice caregiver experiences of relationship in this setting. In so doing, the ways in which delirium affects good death practice are elucidated. Distressful delirium interferes with good deaths by undermining the hospice as a safe place for dying. This happens not only as a result of patient and family discomfort and suffering, but also through total transformation of the caregiving relationship. Delirium thrusts hospice caregivers into roles of vigilant monitoring of patient behaviour and regulators of family's borrowed space. The threats that delirium poses to dying well are not insurmountable, but requires adjustment to the relational dynamic that the circumstances of delirium appear to impose.

Chapter 7: Engaging with Mental State

Introduction

In the previous chapter, I introduced the notions of mental suffering and mental wellbeing as organizing constructs through which the quality of a patient's dying can be interpreted by hospice caregivers. Ways in which caregivers conceptualize end-of-life delirium were suggested. I suggested that elucidation of the relationship between delirium and good dying depends on context rich interpretations that transcend purely objectivist characterizations, i.e., whether or not the patient "has delirium." In this chapter I continue this discussion, elaborating on how hospice caregivers engage with the patient's *mental state* in the context of good death practice. Mental state is the term I use to refer to a patient's overall experience of mental suffering or mental wellbeing. It includes but is broader than conventional understandings of end-of-life delirium.

Knowing the Patient's Mental State

Assessment comprises the major activity of hospice caregivers' work. In every interaction with a patient and a family, assessment is taking place. I have been surprised and impressed many times during fieldwork to listen to a nurse's detailed observations and insights about a patient or family after having spent only moments with them.

In observing the nurse talk with the physicians, I was amazed at how developed and detailed the nursing assessment was. In this case it was about the patient's nausea and vomiting, but this general observation holds for the type and character of nursing assessments here. Nurses are not oriented toward interpreting and describing patient symptom experiences through a lens of preset categories (e.g., "Patient complained of nausea, medication given with relief") as I have observed in hospital. Rather, these nurses seem to develop more detailed and sophisticated accounts based on their observations and interactions. At one point, while watching and listening to this report, I thought to myself "I would want her to be my nurse if I were dying". I don't know what this feeling means for the research, but it seemed important to note. -*Fieldnotes*

According to Tanner et al. (1993), knowing in clinical nursing practice refers to how nurses understand their patients and grasp the meanings of situations for them. These authors assert that in expert practice, "this kind of knowing is very different from the formalized, explicit, decontextualized data-based knowledge that constitutes formal assessments, yet it is central to skilled clinical judgment" (p. 273). By interviewing

practicing nurses, these authors sought to discover what nurses mean when they talk about knowing a patient, and what difference knowing a patient makes in clinical care. Knowing according to their interpretation means having a sense of the patient as a person, and being familiar with the patient's unique pattern of responses, e.g., "how she moves, what positions are comfortable, how her wounds look, how [she] eats, ... what timing of care works best" (p. 275). Knowing is "broader" (p. 277) than what can be captured through formal and reductive assessment practice. An important advantage of knowing the patient to good clinical judgement is being able to draw qualitative distinctions in assessment by "comparing the current picture to this patient's typical picture" (p. 278).

Interpreting the suffering or wellbeing of any hospice patient in this setting relies on a constructed understanding of who this patient is, i.e., their typical picture. In this way, current and typical pictures are a constant source of comparison, reflection, and analysis. Knowing the patient enables hospice caregivers to recognize and respond to potential situations of mental suffering or mental wellbeing. Knowing the patient is an important value of hospice caregivers, and coming to know the patient happens through an iterative process of relational engagement and team communication. Hospice caregivers collect and interpret information through interacting with patient and family, and deepen their insights and perspectives about what this information means through interacting with the team.

Relational engagement.

Practices of assessment in this setting are underpinned by an ethic of engagement. As described earlier in Chapter 4, relationships between hospice caregivers and care-recipients (patients and families) provide the social fabric of the hospice as a safe space. As one nurse participant summarized:

...what we try and do here is to build connection. –*Registered nurse*

Connection is important not only to create a safe place for patients and families to experience compassion and comfort, it is also an asset to the hospice caregiver in coming to know the patient and interpreting their needs, wants, and responses.

Hospice caregivers come to know their patients as they develop relationships with them and their family members. They show strong interest in elements of the

patient's personal biography and narrative life history, their likes and dislikes, and particularities about their personality. It is important to note that knowing the patient, in this sense, does not have to mean cultivating deeply personal knowledge that is generally only accessible through lengthy and intimate relationships. Patients and families pass through this setting at too quick a rate (i.e., average length of stay is less than two weeks, half of the patients die within five days) for these types of relationships. Rather, hospice caregivers engage fully with the person that is here within the confines of the current situation. They aim to relate to the patient with a fundamental and absolute respect for their lived life as a human being. Being known in this context resonates with descriptions by Thorne et al (2005), in which one cancer patient commented, "She [health care provider] was extremely busy, but the three minutes she had with you she was totally focused on you. . .and it was never the medical stuff, it was 'how are you feeling?'" (p. 891).

Hospice caregiver assessments around mental state are basic and general. They happen through personal interaction and center the question, how is [first name of patient] doing today? Dimensions of assessment are revealed through the language that hospice caregivers use in their documentation and their talk. During my fieldwork I was witness to a wide variety of terms used to describe patients' mental state: disoriented, relaxed, scared, agitated, grumpy, happy, restless, calm, upset, forgetful, quiet, thoughtful, fed up, tired, confused, unsettled, suspicious, aggressive. Hospice caregivers use common sense and everyday language to describe what they see and to interpret what it means for the patient's experience of comfort or distress.

Hospice caregiver assessments of mental state happen largely through deciphering the patient's thought process as well as the level of connectedness to his or her physical and social world. Hospice caregivers are alert for changes in their patients' typical patterns of interaction with the world around them. For example, hospice caregivers will notice when a previously talkative patient now seems to be less conversational. Thought process is expected to change and slow as the patient dies, and therefore this is something that is watched for and acknowledged when it starts to occur. In the following example, the nurse shares her impression that her patient's thought processes are slowing. Hospice caregivers' assessment of this situation seem to

rely on an overall interpretation that this patient is showing less vibrancy as he progresses toward death.

Team rounds discussion, Mr. J:

Nurse: Today he's not eating. He's tired. It takes him time to think – he doesn't think of food.

Nursing leader: Is he delirious?

Nurse: I don't think so.

The group notes that he must be tired because the music in the room has gone down.

Psychologist: So there's been a change since last week. *-Fieldnotes*

Patients perform their cognitive (in)abilities through interaction with their families and with hospice caregivers. As introduced in Chapter 6, it is through such interactions that patients are evaluated as being cognitively present or in another *place*. The metaphorical use of place as felt absence of the delirious person is common and can be found in the delirium literature. For example Wong et al. (2010) describe a clinical scenario in which an elderly man's daughter explains her father's hyper-alert and restless behaviour as, "This is not my father. Right now, he's in his own little world." (p. 779) In this setting, hospice caregivers engage similar metaphorical descriptions when they speak of patients as "lost" or "not with the world." When patients evidence disconnection from their environment, the priority question becomes whether this new place that the patient inhabits is liveable, or whether it is a source of distress. Occupying a different cognitive place can also be a source of concern to caregivers when patients express needs or desires that are not compatible with their current situation, e.g., wanting to get out of bed when they are too weak to do so.

Night nurses arrive and begin informally discussing patients with the evening nurse in the nursing station. Ms. P had several bowel movements tonight, and wanted to go in the commode, which she is unable to do. The nursing assistant comments that: "She's not all there." *-Fieldnotes*

When patients appear to hospice caregivers to be disconnected, clinical reasoning begins with consideration of whether this is truly a disturbance or whether there is another more benign explanation. There are several reasons that a patient may appear disconnected, and hospice caregivers account for and document their not-knowing around these instances. For example, a nurse might note in the patient's chart that

while the patient seems “confused,” she is unsure whether this might be explained by the patient’s hearing impairment, or that he or she was just waking up. Another patient whose engagement with hospice caregivers seems to indicate cognitive impairment may alternatively be “tuning out” intentionally, because there is “so much going on,” i.e., coming to terms with her own death.

When patients appear disconnected through interactions with those around them, nurses engage in rule-out hypothesizing as to possible causes for this. In this setting, the first explanation considered is that the patient is experiencing physical pain, particularly if there are other signs that can indicate either pain or delirium, e.g., increased movement. As discussed in Chapter 6, physical pain is primary, and therefore is accounted for before caregivers engage with other possible explanations for perceived distress.

If you do the process of elimination, you do all the other things first, before you get to, before you realize that it is a delirium. Cause you don’t know the patient. You’ve got signs, you’ve always got signs, but you’re not sure, at first. But you’re heading that way, you’re heading down that road...But you can tell, somebody comes from the hospital say and they’re thrashing around in bed and they’re not responding to you. Sounds pretty well like they’re in delirium, but let’s do the pain thing first. –*Registered nurse*

Another common hypothesis is urinary retention, which is common in dying and is known to greatly contribute to restlessness and agitation. The following example is an interesting illustration of delirium as an embodied experience, in which physical and mental dimensions of wellbeing integrate together to generate an overall situation of restless dying.

Change of shift report by nursing assistant:

Mr. L: Very bad night. Restless, agitated, very short of breath. They [night nurses] gave him 3 breakthroughs and put the [abdominal restraint] on. This morning it was the same thing. Restless, wanted to go to the bathroom...I could not get him up, so I put a foley [bladder catheterization] and got 700 [milliliters].

Other nursing assistant: Good for you!

Registered nurse: No wonder he was restless! –*Fieldnotes*

Team communication.

Coming to know a patient's mental state involves piecing together disparate sources of information based on multiple interactions with multiple people. Hospice caregivers keep track of their evolving knowledge of a patient and family through their documentation and their talk.

Nursing admission note of Mrs. D:

Somnolent, eyes closed, responding occasionally [with] one word answers. Difficult to assess cognitive status. Appears reluctant to allow care or stimulus. Unsure if pain is the primary reason for wishing to remain undisturbed. Received 1 breakthrough of morphine 10mg SC [subcutaneous] @ 1300 with apparent effect but unable to adequately assess as patient sleeping.

This note by the admitting nurse reveals how the interactional context between caregiver and patient influences practices of assessment and intervention. The nurse admits uncertainty as to "cognitive status" resulting from the patient's relative non-engagement with her. The nurse seems to attribute agency to this non-engagement, i.e., "reluctant," "wishing." Without any concrete evidence one way or the other as to the patient's overall comfort, the nurse administers medication. With this note, mental state has been introduced as a parameter of assessment, and this will be followed up on through subsequent interactions with other hospice caregivers.

When dialogue between patient and caregiver is not possible, mental state is still very much part of the team assessment. Caregivers approximate the patient's overall sense of wellbeing or suffering through observations in facial expression as well as body movement and posture. Here again, we see caregivers engaging with mental state as an embodied experience. Hospice caregivers are also likely to err on the side of inferring mental suffering when their understanding of the overall patient and family situation implies great sadness. Typically such situations are cases that are perceived by hospice caregivers to be particularly tragic, e.g., a young patient who is leaving behind young children.

The evening nurse introduces the night nurses to the patient admitted today, a man in his early forties (Mr. B) with hemorrhagic brain metastases who had a bleed about a week ago. He has a ten-year-old son. According to his wife, he was "normal" a week and a half ago. There is repeated mention of the patient's young age, "too young," and an exchange of sad looks and frowns between the

nurses. The evening nurse explains that the patient is “awake” but doesn’t really talk (the only thing he said today was “macaroni and cheese.”) His wife says that he nods *yes* to everything because this takes less energy than shaking his head *no*. Earlier in this shift the nurse gave him a Lorazepam (a benzodiazepine), to help “take the edge off.” -*Fieldnotes*

Assessments around possible delirium center whether the patient is connected (or not) to his or her surroundings. When a patient is not communicative, judgements as to delirium hinge on the look in a patient’s eye and family member opinions of patient connectedness. Hospice caregivers and family work together to develop a shared understanding of what the patient might be experiencing. Families will report to the hospice caregivers what they observe. They are the ones who spend the most time in the room with the patient, and they also know the patient best. Hospice caregivers will then relay these observations in their documentation and their talk, e.g., *According to the patient’s daughter, the patient appeared to have a hallucination.* The following example is about the same patient, Mr. B referred to in the above excerpt, eight days later.

In the nursing station, the physician and nurse talk about Mr. B. The physician wants to know what information the patient’s wife has on the effects of the intracranial bleed, as she wants to lessen the wife’s “guilt” that the patient is not talking to her. She brainstorms about whether everything that we’re seeing in this patient, i.e., not talking and closing his eyes when you speak to him, is attributable to the frontal lobe hemorrhage or whether he might also be depressed. She has started him on an antidepressant to see if that will “pick him up.” The nurse asks if he might be in hypoactive delirium. This gets the physician thinking and she muses, “How would you know?” The physician reasons that because he is not talking, because of the frontal hemorrhage, you can only go on “the look” in the patient’s eyes. She says when she looks at the patient he doesn’t “look lost,” and she asks the nurse if she finds he looks lost. The physician then left to talk with the patient’s wife. When she returned she says that no, he’s not delirious, that the wife says he’s oriented, knows where he is, and recognizes people. There is no explicit discussion of how the wife knows this. -*Fieldnotes*

Documentation.

Nurses, physicians, social worker, and psychologist document their assessments in the patient chart. Nurses also write assessments on the report board, their nursing care plan sheets, the flag sheet for physicians, and the grief assessment form.

In acute care, nurses are trained and socialized to chart-by-exception (e.g., Smith, 2002). This means that nurses document their assessments according to pre-set parameters, and narrative descriptions of the patient's state and experience are only indicated when something is assessed to be outside the range of what is expected. In contrast, in this setting aspects of the patient and family experience that are considered important and worth documenting are not limited to the exceptional. Conventional separations of mundane versus out-of-the-ordinary circumstances do not apply. In the nursing notes we will typically read about a patient's good mood when they woke up in the morning, descriptions of the toast and coffee that they consumed, and descriptions of the bed bath received, lotions applied, and patient's response to all of this. In this way, documentation is an important means of coming to know the patient, as described above. Narrative descriptions of the patient's experience in hospice contained in the chart provide details about mood, personality, and family dynamics.

Written documentation serves a multitude of purposes. First, the patient chart provides an official record of the care delivered and the responses to such care. Patient charts are archived at the hospice following patient death. Second, written descriptions of patient and family experience and care given create an uninterrupted and detailed narrative that caregivers can catch themselves up on as needed. A nurse coming on shift after a series of days away from the hospice and picking up a patient, who, for example, has already been in the hospice for five days, begins to know this patient and family through the chart. Third, writing down information seems to have moral significance for nurses, much in the same way as Robinson-Wolf (1988) observed that change of shift report is morally significant. In writing down their assessments and what they did during their time with the patient, caregivers are communicating to the team that they did their job, that they were available and supportive to the patient and family, and that any deviations in wellbeing and trajectories of dying well did not escape their attention.

Despite these functions, the written record only provides team members with snapshots of the experience-as-lived for patients and families. While written records provide a rough outline to assessments made and care provided, this information is further enriched and contextualized by the continuous oral communication amongst

team members.

Mr. J died after 15 days in the hospice. On the grief assessment form, the nurse has indicated that yes, there should be a quick follow-up. For reason, she has written: "Wife – upset, nervous." For comments, she has written: "Entered room to find patient taking final breaths. Wife informed of patient's death – initial reaction was shock 'I didn't think it would be tonight.'" -*Fieldnotes*

In this example, the information as contained in this form seems insufficient to justify a "quick" follow up; feeling upset, nervous, and momentarily in shock are typical reactions in the immediate moments after a loved one dies. Rather, the rationale for referring this family member for a quick follow-up is found by interpreting the reaction to her husband's death in the context of the team's collective understanding of this family's dynamics and coping resources, that they have come to know over the fifteen days of this patient's stay. This collective understanding is built and communicated primarily through oral mechanisms.

Talk.

Hospice caregivers in this setting spend much time talking to each other about their patients. They talk in the medication room, in the nursing station, formally through rounds and report, and informally over coffee and meals. These discussions center the interactions caregivers have with patients and with family, with each caregiver adding their own small pieces of data and interpretation, generated moment to moment through their ongoing and evolving relationships. In this way, team talk contextualizes isolated sources of knowledge, collected at discrete time points. Through these conversations caregivers construct a composite puzzle in striving to portray the patient and family in a holistic sense.

I spoke with the nurse about how Mr. E is doing today. Apparently he's very drowsy, likes to sleep. She says, "When he sleeps he doesn't have to think." I asked if his thoughts make him anxious or nervous. She said he doesn't talk so you have to guess. She hypothesizes that he doesn't want to bother his daughter or others with his thoughts, but "when someone is taking Ativan three times a day, that tells you something."

I talk with another nurse about Mr. E. She says that yesterday she noticed that he talks, then stops, then keeps talking. So, she decided not to just leave the room and assume he was finished, she stayed with the silence, the pauses. Indeed he did open up, and cried with her. He stated that, "you're born, and

everything is downhill from there.” She found this a very intriguing statement, and leads her to hypothesize that he is in emotional pain. She feels it’s probably very difficult for him to witness his own deterioration. He is someone who has always been a “fixer” (this was also discussed at report). I asked her if he has any symptom control issues – apparently not. The syringe driver (Hydromorphone and Midazolam) was started yesterday and Mr. E. is very pleased, stating that he should have done this a long time ago. She relates this attitude to his disposition as a “fixer”, i.e., the syringe driver is “fixing” his physical pain. She explains how emotional pain is more elusive, “You can’t always put your finger on it.” She reports that Mr. E has said [not to her] that he would elect for euthanasia if that were a possibility. *-Fieldnotes*

On the same day as my conversations with these two nurses happened, the physician wrote in the chart that Mr. E “does not talk about his distress nor about death despite an opening to do so.” In these three different accounts, we read multiple interpretations of the patient’s situation that, on their own, have less meaning than when put together. By integrating each account a more complex, nuanced, and comprehensive understanding of lived experience is made possible. Mr. E is not a big talker, but does have something to say. His mental state is at stake, but he seems to relate differently to different caregivers at different times. Perhaps he did not engage with the physician because of his own relationship with this particular caregiver, or perhaps at that particular moment he was just not in a talkative mood. Regardless, what is important is that coming to know this patient involves a team effort in which diverse perspectives and experiences are put together in a synergistic way. Through team talk, hospice caregivers attempt “an intertextuality that works hard to leave nothing out” (Cameron, 2006, p.27).

David: And then you’re all talking to each other all the time

Yeah you’re relaying. And some people see things, again as a team some people might see things that another nurse will say you know actually I don’t think it’s so much that so, but that’s all part of the process of figuring things out for a patient. *-Registered nurse*

The role of figuring things out for a patient becomes important in dying as patients lose the ability to speak for themselves about their own perspectives, experiences, and choices. Again, in a context in which cognitive access is diminished

and mental state is at stake, hospice caregivers band together to construct a shared understanding of what is happening and what needs to happen to ensure that they are still on the road towards the good death. In the following example, the team reconciles their understandings of the patient's wellbeing, who previously seemed at peace with her dying but now appears delirious and uncomfortable.

Morning report with MD, for Ms. I:

Nurse: "Dying, delirious" "She doesn't look good, seriously."

MD: syringe driver?

Nurse: Yes

MD: She was very zen about dying though-

Nurse: Oh she's not zen now!

Other nurse: And neither is her mom, there's no zen in that room!

(laughter)

Nurse: She's very suspicious, especially suspicious of her mom

Nursing leader: "Her mom's driving her freaking nuts"

Other nurse: She's slipping and she knows she's slipping.

Psychologist: She needs to be in control and she can't anymore

MD: Opinions on treatment?

Other nurse: She's dying on her feet. She's being dragged to the bathroom. It's pitiful.

Nurse: She has to sleep now. -*Fieldnotes*

Over the time that this patient was at the hospice, hospice caregivers came to know her as a very private woman whose sense of control was very important to her. Knowing this enabled for hospice caregivers a context-sensitive interpretation of this patient's personal delirium experience and the distress involved, "she's slipping and she knows she's slipping."

Continual sharing of information and hypothesizing amongst hospice caregivers serves to generate a synthesized angle of vision through which individual patients and families are known in this setting. It is important for hospice caregivers to be on the same page with each other concerning what the priority issues are and what their role will be in providing for a good death. Development of such a shared understanding sometimes begins even before the patient and family arrive at the hospice. Often someone (either one of the nursing leaders, liaison nurse, or physician) will have developed a pre-understanding of the patient's story, either from having cared for

them in the community (in the case of some of the physicians or liaison nurses) or more commonly through communication with the transferring treating team. During change of shift report the night nurse will relay whatever information she has about an incoming admission for the day shift, and this report is sometimes so detailed that it strongly resembles discussion of a patient already in the hospice. Through such pre-understanding, hospice caregivers begin to make decisions about how they will plan and organize their care.

The nursing leader discusses another admission with the physician in the nursing station. The patient will be coming from home, he has liver and brain metastases, and is confused. Will urinate on the floor and then realize, 'Oh, I just urinated on the floor.' Will put pills in his mouth and then not know to swallow. So, "inappropriate behaviours" are making it more difficult for the patient to stay at home. Another nurse then enters the nursing station and joins the discussion, "Is he confused?" The nursing leader says that yes, he is. "Then we'll put him in #8". The rationale for this is that #8 is the closest room to the nursing station, enabling better vigilance and supervision. *-Fieldnotes*

Hospice caregiver certainty/uncertainty.

Discussions of patient's mental state by hospice caregivers are often vague and nonspecific. For example, during report a nurse might describe a patient as a "little bit off" or as "not all there," without elaborating further. Other times, the word delirium may be used but with a vague qualification; for example, patients might be known as "a little bit delirious" or to be in "full-blown delirium." When this happens, however, other hospice caregivers seem to understand what this means.

David: And then speaking of words, when you're kind of making your own assessments or communicating things to other shifts, do you find the word delirium is used a lot among the nurses?

If it's a full-blown delirium, yes. If not, it's just, they'll say well slightly disoriented, slightly confused. Uh, but reoriented to time and place and um, reassured. You know reassurance given...Just to re-orientate them, sometimes you can't. Sometimes they are out in left field.

D: And then, 'cause you used the term full-blown delirium. So, like what, is that what you mean, when somebody's way out in left field?

Oh yea. Yes that's what I mean. That's when they're really, I mean they're agitated, and there's no convincing them of anything. *-Nursing assistant*

In this setting, nurses have talked with me about how “confusion” as a descriptive term is unhelpful because of its non-specificity.

I think that’s where I see a little bit of, you know it’s, you know calling people confused. I mean I’ve done it in my charting too. But confusion is a symptom. It’s not, you know it’s a symptom of something else. –*Registered nurse*

Another nurse once told me that at the end of a long shift, nurses are tired, and it is easier to merely write “patient confused” than to document a more elaborate assessment about the specifics of the confusion for that particular patient, though she was critical of herself in admitting this. Over the course of fieldwork, I definitely noticed, upon review of selected patient charts, that generic descriptors of confusion were often used, e.g., “slightly confused,” which on their own do not convey anything particularly meaningful. I would wonder how such documentation could possibly be helpful to the patient’s care. It appears, however, that labeling patients as confused, or using other common sense surrogate terms such as “off”, “in his own world,” is an important aspect of hospice caregivers’ communication with each other toward figuring out the patient’s mental state. The reductive, objectivist, and clinical language that is encouraged by advocates of a more ‘specific’ and ‘systematic’ approach to mental status assessment encourages a definitiveness in diagnostic reasoning, which may be incompatible with the ways nurses strive to represent the subtleties and nuances of their patients’ unique experiences (Cameron, 2006). Adopting a purposefully vague language communicates that mental state seems to be at stake in a particular situation, while still accounting for uncertainty about what is happening and what it might mean. In this way, this practice can be conceived as artful application of unknowing in nursing (Munhall, 1993; Schott, 2009), whereby nurses strive to learn of their patients’ unique experiences while staying open to interpretive possibilities that might more fully account for that which they do not yet know. When mental state is identified in any given case as a priority area of concern by the team, documentation becomes replete with common sense descriptors. On their own, these descriptors do not mean much, but when put together and integrated with team member talk that is happening continuously, hospice caregivers paint an overall picture of the patient’s mental state and the implications of this for his/her good death.

The assessment practice of hospice caregivers happens through a balance of knowing and not-knowing regarding the relationships between delirium-exhibiting behaviours and mental state. Interpreting what they are witnessing in their patients involves a continual process of integrating their initial impressions that something is afoot, with uncertainty over the exact nature of the suspected disturbance and its significance. Even when patients are not able to communicate distress through coherent language, i.e., “This is distressing to me,” certain manifestations of delirium are easily interpreted as suffering.

If the guy’s hyperactive and you know he’s all over the place and you know he’s talking a mile a minute, I know he’s uncomfortable. Uh, if he’s paranoid, I know he’s uncomfortable. -*Physician*

Other instances, however, are less clear.

I ask the nurse about Mrs. Z, if she is “cognitively stable.” She says it’s hard to say. She had her for the first time last evening. She tells me that after receiving a telephone call from her mom, the nurse went to check on her and Mrs. Z said “that fucking bitch” (referring to her mother), talking about how she never cared for her and is mad because she wanted to die first. The nurse also noticed that Mrs. Z talks about herself in the third person, “Z doesn’t like it when her mother calls.” The nurse tells me that she doesn’t know whether what she’s observing is normal for the patient or not. She seems to be trying to determine what is ‘appropriate’ in the context of who this patient is. -*Fieldnotes*

In this conversation, the nurse also mentioned to me that the patient’s mood can change from one moment to the next, and she suggested this as a particularly interesting case for my purposes (as the research student doing a study on delirium) because “there is something there.” Another nurse noticed such sharp changes in affect as well, referring to this patient’s communication as “inappropriate,” and citing her rapid alternation between rude, harsh and insulting comments to caregivers one minute and then becoming kind the next.

In the following description of a conversation with a nurse around her caring for a particular patient, similar tensions in ascertaining mental state are apparent. Specifically, this nurse’s narration simultaneously evidences elements of certainty and uncertainty around what she is witnessing in her patient and whether the patient is suffering.

The nurse tells me the patient is “not quite there.” I ask if this is a recent development. The nurse tells me that it is not, she’s always been like this, but today it’s more “persistent.” She found that this morning the patient was disoriented to place and time but easily reoriented, resuming “appropriate communication.” But again this afternoon, after lunch, the patient was even more profoundly out of it. However the nurse is clear that she believes that this is not disturbing to the patient, so she “leaves it.” She also talks about how the patient has never been a big talker, but that it is clear that she has a lot going on in her head. The nurse will ask, “What are you thinking?” because her assessment is that the patient, with her eyes open wide, is thinking hard. She will also ask if she dreams, and apparently the patient has told her that she is having nightmares. Apparently she does not remember the content of these nightmares, just that she is having them. This does not sit well with the nurse. To her, if a patient is having nightmares, things are not well. But she then resumes talking about how the patient’s confusion/disorientation is not distressing to her, and how it is important to not be overly “interventionist,” which she clarifies refers to giving medication.

I am not too clear on the apparent contradiction between the nurse’s assessment that the patient’s confusion is not distressing and that she is having nightmares. Are these seen as entirely separate issues? It doesn’t seem so as the nurse herself wove them together in her conversation with me, where I did not offer any leading or probes. -*Fieldnotes*

Insofar as assessments of mental state are dependent on relational engagement, connection, and knowing the patient, the problem of cognitive access becomes important. As discussed earlier, access to the patient’s subjective world is greatly diminished in delirium. Throughout my fieldwork, the notion of patients “not making any sense” recurred in hospice caregivers’ language when referring to those whose mental state was cause for concern.

D: How do you know if somebody is delirious?

Um...My experience with that is someone, I would say who was very agitated, trying to get out of bed. Uh, might be hallucinating. Might be, uh, speaking...when they’re speaking they’re not making any sense. They don’t seem to be, sometimes, not always but sometimes, not aware that you’re there trying to help them, or anybody is there trying to help them. And they just seem to be inconsolable, which is a good word, I think. And they can’t tell you, and sometimes the patients might be semi-conscious, they might be unconscious, they might be totally conscious. But they can’t seem to tell you often times. But you know there’s something’s wrong.” -*Registered nurse*

In the above excerpt from my interview with a nurse, it is apparent that the nursing assessment involves balancing a sense of certainty that “something’s wrong” with uncertainty over the very nature of the patient’s suffering, where patients in delirium are difficult to understand, are unaware of others’ support, and can’t communicate the specifics of their discomfort. When hospice caregivers are not able to connect with their patients and are not able to interpret their subjective reality with confidence, they worry as to how the patient might be experiencing the interaction with them.

I find that delirium is, is a particular challenge... Because there are many reasons for people to be distressed. And one of them may be just sheer frustration that they can't express what they want to do, or what they want to say. It might just be, 'Leave me alone, I don't need a bath now.' Or 'Don't move me.' You know? ...But they are so incapacitated. So, such a disadvantage when you can't speak for yourself –*Registered nurse*

Whether because of delirium or because of some other problem, a patient who is not able to express their own agency due to conscious, cognitive, or communicative disturbance thrusts the caregiver into a position of uncertainty regarding whether the care they are providing is optimal and whether they are indeed on the road to the good death. One patient for example suffered a stroke while in hospice that rendered her aphasic, i.e., unable to express speech. This case caused the team much concern and sadness. As the patient deteriorated and eventually died, they found that she did not seem comfortable, appearing frightened and anxious. They were frustrated on her behalf at not being able to express her own needs, and concluded that she was a “prisoner in her own body.”

Concern over not-knowing the patient’s subjective experience is also a preoccupation of family members, who spoke with me about the challenge of “not knowing what this is like” for their dying loved ones. In these situations, the patient who *looks peaceful*, e.g., sleeping, is an extremely important resource to hospice caregivers in reassuring family members that things are going as well as they could be, and that everything is being done to ensure the patient’s comfort.

Despite the challenges to relational engagement that altered mental state can pose, caregivers remain careful to continue to treat the patient as a moral agent when cognitive access is diminished. This means that they recognize that personhood and

dignity remain at stake and they tailor care in ways that honour the patient's identity as a human being. Prior knowing of the patient, however, is helpful in being able to achieve this.

David: To be able to provide nursing care to somebody, how much do you depend on the person's level of interaction with you, cognitive acuity, in order to be able to carry out that care?

I think that connection's still there, I like to think that with patients that are very somnolent, and many of our patients, most people die not conscious, so most of our patients will be in a sleeping state at the time of death right? ... it's nice when you've gotten to know your patient before that, but they're very much, they're not objects that you're caring for, they're people, so um, you're still very much caring for a person. –*Registered nurse*

David: What's your perspective, experience with patients who are delirious, confused, disoriented, whatever?

My perspective is, it's the disease that's causing that. And I still try to treat them as, very much a human being with a disease. So I may not talk to them as much. I may use touch if I sense there's not going to be a pulling away from that. I may use stroking, depending on what I know about the patient. –
Volunteer pastoral care provider

Search for meaning.

Perturbations in consciousness, cognition and perception in dying are a source of wonderment for hospice caregivers. As one patient care attendant mentioned to me over dinner one evening,

"It's just incredible. You wonder where the brain goes. It's incredible." –*Fieldnotes*
Similarly, the psychologist stated during our interview that,

When you go home at night you wonder, what function does that serve in the brain? Why is the brain doing that, at a physical level? –*Psychologist*

A volunteer at the hospice once remarked to me that when someone is "confused", there is usually some meaning underlying their communication and behaviour, and that in her experience, confused patients can sometimes become more "aware" when there is something meaningful to return to. To this end, hospice caregivers engage in searching for and assigning meaning to the delirious manifestations to which they are witness. In the following example, a nurse explains

how seeking out the meaning underlying delirious manifestations facilitates her engagement with the patient.

David: Talk to me a little about delirium, what do you think about delirium?

That's something, it's strange eh? That's something I like to work with, with the patient. Because even if it's delirium, it could look sometimes so, bizarre, and so strange, but there's always a little bit of truth in the delirium.

David: Ok

Even if the patient has been uh, because medication or whatever, or the sickness, there's always a little bit of something you can go and get. And that's what I like. That's why I like to try and find out what is behind that. And then they kind of, you can guide the patient even with that little information. –
Nursing assistant

This nurse continued in her interview to talk about the importance of engaging with delirious patients as a necessary element of quality care. She prefers connecting and responding to her delirious patients rather than jumping to sedating medications that she says might make the patient *look* peaceful, but do nothing to help the patient through whatever issue is the actual source of his or her discomfort.

Like we had a patient, he was afraid. But then he was, he was more sedated and sedated. But in his delirium, he keep saying, 'I have to cross a wall, I have to cross a wall.' And he, he was moving [imitates restless movement], and it's one of the [patient care attendants] who sat with him and [patient said] 'You come with me, I have to cross the wall.' And she was good enough to tell him, 'You cross the wall, but I cannot go with you.' You see? You kind of have to, still believe that you have to work with the patient, even in their delirium. But if you put them too much asleep, I think we're kind of just, we avoid. –*Nursing assistant*

Understanding a patient's delirious communication or behaviour as meaningful depends on knowing and engaging with elements of the patient's biography, which then facilitates response. For example, a particular delirious patient who evidenced much paranoia, fear, and mistrust towards hospice caregivers was understood to possibly be reliving traumatic experiences having lived through a war as a child. Her daughter shared with me that, in her opinion, the best way to interact with her mother when having hallucinations or illusions of frightening characters was to confirm their existence and to reassure her that they were not a threat.

If Mrs. H is eyeing someone suspiciously, her daughter, Mrs. D, will reassure her by saying, "She spies with us." This reassures her mother that this new character is "on our side," while not denying her perceived reality that this is a wartime situation of spies...When Mrs. D was feeding her mother yogurt, Mrs. H didn't want any because it was poison. "We'll die," she said. When Mrs. D told her it was okay, it was just yogurt and gave her a bite, Mrs. H said, "That's it, you're dead." Again, Mrs. D talked about staying with her mother cognitively, reassuring her mother that, "It's okay, we'll die together." -*Fieldnotes*

When caregivers do not know the patient well enough to interpret the underlying meaning of communication that does not make sense to them, they nevertheless are alert to the possibility that there may be significance to what they do not understand. They then seek out further information from colleagues or from the patient's chart, as in the following example.

The nursing assistant comes into the nursing station, saying "I have to read about [the patient in #3]." Apparently he said to her, "We have to go," and when she asked where, he said, "To the airport, we have to get to the funeral." She then asked him whose funeral, and he replied "Mine!" I ask her how she responded. She asked him if he thinks it will be soon and he said yes, he was ready. She reassured him that he didn't have to go anywhere, he could stay here "with us," and she told him that, "We will take care of you." She struggles for the right word to describe his state. "Would you call that agitation?" she asks. She does not use the word delirium. -*Fieldnotes*

The assumption that a patient's seemingly nonsensical communication or behaviour may have meaning is important because it positions the caregiver in a role of reflective questioning around how this patient can best be supported in his or her dying. The restlessness associated with delirious dying alerts caregivers that something may have been missed in providing for the patient's good death, and provides a "door" to engaging with family about what that might be, as explained by a nurse in the following excerpt. These comments are in response to my asking her how she supports family members when patients are in delirium.

And sometimes we can say, 'Do you know of any issues that maybe this person might be agonizing over? Or something that they're trying to resolve in their head, maybe they're afraid to leave?' I would try to explore that with the family I think, and sometimes you do get an answer. Sometimes you get an answer, well such and such who lives in California, this patient hasn't seen their father, hasn't seen this person for twenty years, or something like that. Maybe that's what the problem is, maybe that's why he's agonizing in his head about leaving, about

dying. And sometimes that issue can be resolved and sometimes it can't. But even so, it gives you a couple of doors to go into with the family, and try to reassure the family, but also try to reassure the patient. –*Registered nurse*

Dimensions of Mental State Assessment

As a practice that happens through relational engagement, assessment of mental state depends on knowledge cultivated through everyday conversations with and observations of patients. Formalized assessment tools are therefore rarely used. Standardized protocols for clinical interviewing described in the delirium literature typically involve having the patient perform certain cognitive tasks, so that the clinician can determine relative capacity-incapacity of mental functioning. Such protocols would not be a good fit in this setting, as such a clinically oriented and medicalized approach would necessarily detract from the countercultural ethos of habitability and comfort that this hospice strives to enact. To adopt mental status assessment tools as a method of structuring interaction between caregiver and care-recipient would:

...take away from the intimacy of the interaction. –*Nursing leader*

Sitting at the nursing station desk one evening, I read a review article on bedside delirium instruments, which interestingly had been left for me by the hospice psychologist who thought I might find this interesting. One of the instruments included in this review is the “digit span test” that is described as follows:

A series of random numbers are presented at a rate of 1 per second. The patient is asked to repeat the sequence. Starting with a 2-number sequence, each correctly repeated series is followed by a sequence with 1 additional digit. The test result is abnormal if the patient cannot repeat at least 5 digits. (Wong et al., 2010, p. 782)

At the time of reading I noted in the margin of this paper that having patients in this setting perform this activity appeared, to me, absurd. Such a practice seems quite disengaging, and antithetical to the overriding ethic here that encourages relational interactions focused on conversation and that follow the patient's lead in determining the pace of the encounter. Most importantly, caregivers here would be remiss to put the patient in a vulnerable position of potentially feeling tested and experiencing undue frustration or failure.

While pre-set categories of mental assessment do not structure, in a prescriptive way, interactions with patients in this setting, established categories do operate as a

framework through which to classify, interpret, and communicate hospice caregiver observations and impressions. The confusion rating scale (Gaudreau et al., 2005; Williams, 1991) provides a framework for nurses to screen for, identify, communicate, and follow cases of delirium. It's completion does not require the nurse to structure her interaction with the patient. At the end of every shift, the nurse will indicate on a scale from 0-2 the extent to which the patient exhibited any of the following: 1) disorientation, 2) inappropriate communication, 3) inappropriate behaviour, and 4) illusions/hallucinations. Sometimes a nurse will not assign a score but will instead mark an asterix (*) to indicate that there was something of note in this category. Usually, the nurse will include a narrative explanation to contextualize her findings, which will describe in detail the patient's interactions with the nurse and/or family members. Nurses and physicians have spoken repeatedly about the difficulties they have making use of this and the relatively small role it plays in organizing care. Hospice caregivers in this setting are much less interested in numerical ratings applied to a particular patient's mental experience as they are in narrative descriptions of how a particular patient is doing, what happened over the course of the shift, whether they are distressed or comfortable, and what they might do to help. Nevertheless, the hospice nurses do complete this form, and therefore consideration of its various dimensions provides further insight into the areas of mental state to which nurses orient their assessments.

Disorientation.

A patient who is "oriented" demonstrates an accurate awareness of themselves, the people around them, and their place in space. Nurses are generally trained to assess for orientation around the three spheres of person, place and time. Patients in this setting often evidence disorientation around place and time, for example thinking it is morning when it is night, thinking it is winter when it is summer, or thinking they are at home when they are at the hospice. One patient once told hospice caregivers that she did not recognize herself or remember who she was. This was a source of great concern for the hospice caregivers, whose faces betrayed their own sadness as they spoke about this patient amongst themselves.

Disorientation is the diagnostic category that most closely approximates general

assessments of mental state that are continually being made and communicated through team talk. When hospice caregivers speak of patients being “lost” or “in her own world” they are speaking to disorientation. The extent to which disorientation is disturbing to hospice caregivers depends entirely on whether the patient seems distressed or not. If the disorientation is a source of mental suffering, for example the patient is frightened at not knowing where they are, then hospice caregivers will attempt reassurance through reorientation.

The appropriateness of reorientation as a nursing strategy in situations of delirium has been critiqued by nursing authors, who caution that orientation privileges the here-and-now reality of the health care provider while denying the lived reality of the patient, potentially leading to alienation in their relationship (Andersson, Norberg, & Hallberg, 2002; Day, Higgins, & Keatinge, 2011). In this setting, speaking to patients in a way that is orienting is not about correcting their ‘misinterpretation’ of reality. Rather, it is an attempt to reassure patients whose capacity to participate deliberately and meaningfully in dialogical relationships is diminished, i.e., to share their perspectives, to recognize and be recognized, to exert their preferences and opinions. In the following example, a nursing assistant describes orienting her patient by reassuring her that other people are present, that her family knows where she is, and that she is safe. She does not correct the patient as to her disorientation to place.

...she was talking away, talking away, talking away. And she has a lot of issues. She has a lot of anxiety. So I just told her, I said you know, ‘It’s time to sleep now, and we’ll talk about it in the morning.’ And she’s been asleep since. But she knows me too. That’s the thing. If she didn’t know me, she’d probably, you know, I mean she said to me the other day, because she was quite, quite confused. I wouldn’t say, not mildly, I would say she’s confused. And uh, she said to me, you know, ‘Where am I?’ She wasn’t sure so I told her. And she asked me if she was in a nursing home, and I wasn’t going to say differently because she had enough issues going on there. I said, ‘Yes you are.’ She said, ‘Are there other people here?’ I said yes there are...and I said, ‘But your family knows you’re here, your son and your daughter-in-law come and visit you, and they know that you’re safe here with us.’ It’s just the reassurance over and over and over, and she goes, ‘Good.’ –*Nursing assistant*

Nursing assessments as to patients’ orientation happens through ordinary interaction. Nurses do not ask the patient to prove their orientation through specific questioning,

e.g., *Do you know where you are?* Rather, the nurse develops a sense of the patient's perception of orientation to his or her surroundings through conversation. The nurse will offer orienting information in the context of that interaction, with the goal of reassuring the patient and making him or her feel safe and comfortable. As the nurse in the following excerpt describes, this relational-interactional approach to orientation is important in ensuring the patient does not feel "judged."

...if somebody is struggling to find out where they are, or looking at you strange, and it's daylight, uh, then I will want to open the blinds. And turn the light on and say, 'Hey, it's breakfast time.' Or whatever.

David: Um hmm.

And try and remind people. Even people who, who are not necessarily delirious, um, have a hard time with, with the concept of time.

David: Um hmm.

And they may have just woken up and they don't quite know where they are.

David: Um hmm.

Or forgetful for whatever reason. Uh, maybe it's organic brain disease, who knows? Um, and a lot of people, it's almost human nature, myself included. If I feel I'm struggling, or I'm, I'm losing, or I don't know where I am, it's hard to kind of say to somebody, 'What time is it? What day is it today?'

David: Yeah.

Because you're, you're fearful of being judged.

David: Right.

You know? Or that's what I see.

David: So you just offer that information up.

Yeah.

David: Right from the get-go.

Sometimes. I try. I try. –*Registered nurse*

Inappropriate communication and behaviour.

As nurses engage with patients during the day, evening, or night, they interpret how the patient communicates and behaves through a lens of appropriateness. This subjective judgement relies on knowing the patient's personality and style of communication or interaction, and then being alert to deviations from what is typical for this person. Judgements of appropriateness are not intended as moralizing practice. Rather, interpretations are made by hospice caregivers about whether the patient's communication and behaviour fits within a larger context of his or her known personality, attitude, and disposition. Nevertheless, wider social conventions certainly influence these assessments, particularly when the hospice caregivers have not yet had time to get to know the patient or family. For example, the behaviour of a particular patient was described as "weird" when she spontaneously proclaimed "I love you!" in somewhat of a singsong voice to the nurse who was helping her into her room on admission. Another nurse then noted that this patient "appears somewhat confused" in saying "I love you" to a patient care attendant after having just met. In the following example, a patient's vulgar language alerts hospice caregivers to the idea that his communication may be "inappropriate."

There is a new admission in #7 – a patient who came this morning from the emergency room of [a hospital]. The nurses laugh in the nursing station. They got him on the commode to urinate, and he remarked, "That's a good leak!" He also referred to his penis several times: "Are you going to wipe my dick?" In response to a question if he was ready to go back to bed, "What – with a wet dick?" The nurse also gave him the call bell, and in response to her saying to call if he needed anything, he responded "Anything? No questions asked?" (The nurse took this comment as sexually suggestive) ... In her conversations in the nursing station, the nurse is trying to figure out whether this behaviour is "inappropriate" (i.e., as a diagnostic label) or if this is his personality. She did observe that when he made these cracks initially, his wife reacted positively: "He's back!" His wife expressed relief at her husband regaining his sense of humour after apparently having had a terrible few days in the emergency department ... Later, in the report with two physicians, the nurse relays the patient's statements and again describes her difficulty in discerning between appropriate communication and the patient's personality. She mentions, "I hate to label" because "then we give them Methotrimeprazine (a sedative anti-psychotic)", and "then...(she makes a motion by raising her hands up and arching her back in her chair, neck back, to illustrate a lifeless patient sedated with medication)." One of the physicians brings up the possibility of frontal lobe

involvement resulting in disinhibiting behaviour, although the group is unclear if the patient has brain metastases - *Fieldnotes*

Hospice caregivers evidence critical reflectiveness around their role in deciding what appropriate means for people whom they do not know well. Discussions with other team members and with family play a large role in helping the caregiver to decipher the meaning and significance of what is witnessed and whether it actually is inappropriate.

David: Is it easier to make those judgements when you know the patient?

Oh yes. Yes of course it is. There have been a few times when I thought it was inappropriate communication and found out it wasn't.

David: That they were just like that?

From the family. Yeah. The family said, 'They talk like that all the time!' You know, oh geez, news to me. [Laughs] Sorry about that! -*Registered nurse*

Certain hospice caregivers are critical of the undue medicalization and labeling as pathology interactions that might appear strange to the person performing the assessment, but that are of no consequence to the patient's mental state and so should be accepted and left alone. In this way, there is tension apparent within hospice caregiving practice of labeling potential manifestations of delirium through identification of inappropriate communication and behaviour, and resisting such labels.

One thing I'd like to say - it's not a question you're asking.

David: That's fine.

But I find a lot of times um, people are too quick to jump the gun, and start saying somebody's changing.

David: Hmm.

... Maybe delirium setting in, when it's a basic human thing to forget what something's called.

David: That's right.

And when they say, "What's that thing?" And next thing you know it's charted, 'Finding a hard time finding words.'

David: Okay.

Like I'm not saying that that isn't it. But if you point something out.

David: Um hmm.

Then people start looking for it.

David: Um hmm.

And you can kind of make it happen. I just. I think people need to be given the right to change naturally, without other people sort of putting too much evidence into finding things.

David: Okay.

And I guess I've, I've seen that a little bit. And I don't like that. –*Registered nurse*

In the above interview excerpt, the nurse speaks to the potential for delirium assessment and management as a disengaging practice that risks alienation rather than fostering accompaniment and support of patients through the “natural” changes of the dying process. This is an important dissenting viewpoint from the prevailing paradigm that conceptualizes delirium as a neuropsychiatric problem to be diagnosed and treated (see Chapter 2). This viewpoint potentially clarifies my observation, described earlier, of the variable use of the delirium label in hospice caregiving practice. The resistance of delirium as a diagnostic label is consistent with a practice that favours holistic engagement with the patient’s mental state, i.e., to what extent the patient is distressed or comfortable, over a reductionist logic that maps patient experience to pre-set categories of assessment. At the same time, however, caregivers in this setting see value in the delirium label. In my discussion with another nurse, she described her view that interpreting a patient’s mental changes through a delirium framework might mobilize better care.

David: ... how clinically useful to nursing is the actual label of delirium?

Well, it probably is very useful I think. Because then you're, you're, maybe more likely to say, okay what could be causing this, and what can I be doing to help reverse it?

[...]

David: ... do you think it affects the management?

Well you're making me think about it, because I think maybe it does. Um, I find people are often reluctant to, to use, they're not really reluctant, but they don't, it doesn't occur to them to use the antipsychotics, as opposed to using the benzos.⁸ [Benzodiazepines]

David: Okay.

Um, you know. Someone who's restless overnight, well why not try giving them an antipsychotic?

David: As opposed to giving them a benzo to calm them down?

Yeah. Yeah you want them to sleep overnight for sure but, or maybe they need a bit of both, but maybe if they, if they were diagnosed as having the delirium, then maybe they would be more likely to use those drugs.

David: Hmm. That's interesting.

Yeah

David: And you find that happens sometimes?

I do find. You hear often, 'Oh you know, they didn't sit still all night.' Or they're um, you know, tossing and turning all night in bed. And, did you give them any Haldol? [An antipsychotic] You know?

David: Um hmm.

Yesterday morning when I arrived, and the patient um, one of the patients was not doing very well, and was quite, had been agitated all night. And did have a PRN ordered Haldol [*Pro re nata*, a medication prescribed by the physician and to be given as-needed at the nurse's discretion], and hadn't received any Haldol. And I, I did give him some, that was one of the first things that I did. But maybe if it had been, you know maybe if he had been labelled as having a delirium, maybe then the nurses would be more likely to do that. –*Registered nurse*

⁸ Current clinical guidelines recommend antipsychotics as the appropriate class of medications to treat the symptoms of delirium. Benzodiazepines, while often used in practice because they mask symptoms by temporarily sedating the patient, can exacerbate delirium (Caraceni & Grassi, 2011).

Hallucinations.

While assessments of orientation and appropriateness of communication and behaviour require a great deal of interpretation by the hospice caregiver, hallucinations represent a more concrete dimension of mental assessment. Reporting that a patient is hallucinating seems less judgemental than identifying them as disoriented or inappropriate. Perhaps for this reason, the nurse in the next example is more interested in reading about her colleagues' assessments of hallucinations, and less interested in others' assessments along the other dimensions previously described.

David: And do you find that rating system [confusion rating scale], or the use of that flowsheet, is it helpful? In directing care, or...

I think the only thing that is helpful in that is the hallucination aspect. If the person is hallucinating, and what part of the day are they hallucinating. If they tend to hallucinate in a certain part of the day. That's the only thing I look at when I tend to look at them. *–Registered nurse*

Many patients are able to describe their hallucinations and state whether they are a source of distress. As with other dimensions of assessment, hospice caregivers strive to ascertain not just whether a patient is having a hallucination, but the meaning that this perceptual experience holds for them. Interpretation of meaning then directs the nursing response, specifically around whether or not medication should be administered.

David: When patients are hallucinating, how does that affect the nursing care? What's it like to provide nursing care for someone who's hallucinating?

Well, first of all, assess whether or not they have it. Are they having hallucinations, what kind of hallucinations are they having? Are they comforted by it? Or does it bring anxiety? And go from there. And if it does bring anxiety, definitely give antipsychotic, to help control the hallucinations. But if they're comfortable with their hallucinations, it's, why ruin a good thing? *–Registered nurse*

Although hospice caregivers attempt to engage their patients' own insight and understanding in interpreting their mental state whenever possible, patients who are hallucinating in delirium are often unable to coherently describe their experience or communicate the nature of their distress.

And one good thing is to ask the patient themselves. When they're having a hallucination, ask them, 'Are you disturbed by what you're seeing? Is it distressing or bothering you in any way?' ... Now mind you, a real delirious patient often cannot give you a real coherent,

David: Analysis?

Analysis of what they're experiencing. And they can't always do the intellectualization, to say, 'Ok well I understand why I'm doing this.' They're past being able to do that. –*Registered nurse*

Nursing interaction with patients experiencing hallucinations that appear distressing and who are unable to coherently describe the nature of their experience appears to correspond to the first level of Gadow's (1995) dialectic of nursing assessment, which she terms "vulnerability." She suggests this is the first layer of knowledge in nursing assessment, defined as the "struggle to understand what is happening." (p. 32) Vulnerability is the level of greatest immediacy, where,

In a clinical situation, immediacy can be translated as urgency. Immediacy characterizes a client's distress when it is not mediated by explanation or intervention. Breathing difficulty [or distressing hallucination], for example, can be an experience of terror when there is no interpretation within which it becomes intelligible. A corresponding immediacy is felt by a nurse who recognizes the person's terror and acts to alleviate the [distress] without pausing to reflect on etiology. (p. 27)

According to Gadow, a nurse's response to the patient at this level will be immediate, "as simple as impulsively reaching for his hand." (p. 27) In the following excerpt from my fieldnotes, I describe a patient who appeared to be experiencing distressing hallucinations, and who seemed "past being able" to interact coherently with her caregivers around what she was experiencing and the meaning of this for her.

I stopped in to say hi to Mrs. B. I did not stimulate her, but she opened her eyes as I approached the bed. At first she seemed calm. I asked if she had been dreaming and she said no. But then she gestured in front of her, as she had when she was describing her visual hallucinations to me two days ago. I asked if she was seeing something, and she said no. But then she said, "They're mixing the two things together to kill me." She made a mixing motion with her two hands. When she said, "kill me," she grabbed her duvet and pulled it towards her slightly. She was wide-eyed. She looked frightened, as though she was trying to hide under the covers. This made me very nervous that only I was present - I would need to tell her nurse that this was happening - it had an

‘emergency’ feel to it. I tried to clarify with her if she was seeing something, or if this had been her dream, but it seemed to be neither. Rather, it was more of a general feeling - The psychologist later called it a “paranoid delusion.” Mrs. B said, “They say it could kill me, I don’t know if they’re right.” I could not ascertain from her who “they” is.

The nurse came in the room within a few minutes... I said, “Mrs. B, did you want to tell the nurse what you just told me?” I then mouthed to the nurse that Mrs. B feels like someone is trying to kill her.

The nurse immediately took Mrs. B’s hand and said “Oh! That’s not a nice feeling.” She asked Mrs. B if she was seeing something, if it was a hallucination, if it was a dream, but did not really get anywhere. She told her she would share her experience with the doctor. -*Fieldnotes*

In the nurse’s immediately taking this patient’s hand, and even in my own perception that this was an “emergency” situation, I see what Gadow describes as immediate, pre-reflective action. The nurse reached out to the patient to soothe her distress prior to engaging in an assessment of what was happening and what might be done. She then left the room, reported what was happening to the physician, who asked that the patient be given a dose of Methotrimeprazine, a sedating anti-psychotic medication. Later, in the nursing station:

The nurse is trying to figure out how to describe what had happened - “it’s not clear” - but she decides she will make her note about the objective aspects of Mrs. B’s experience purposefully vague - she doesn’t want to be too specific and thinks it’s more important to convey and communicate the feelings than the facts. What is important is not whether it was a hallucination or a dream - what matters is that the patient felt scared and persecuted. -*Fieldnotes*

While I started this section by introducing hallucinations as a more “concrete” dimension of mental assessment than orientation, communication, or behaviour, this example shows that engaging with a delirious patient around hallucinatory experience is not straightforward. Here again, this nurse shows a partiality toward a practice of assessment that is “purposefully vague,” that highlights thoughts and feelings rather than labeling the patient’s experience. In the end, we do not know for certain whether this patient woke up from a bad dream, was having a visual hallucination, or experiencing a paranoid delusion. What we do know is that she was distressed, and that her nurse responded to her with the resources available to her, i.e., supportive

presence and anti-psychotic medication. The example is an illustration of the balancing of certainty with uncertainty, described earlier, as to delirious manifestations, their implications for the patient's mental state, and the best way to respond.

Clinical Delirium Management

When presented with manifestations of delirium, the first step in hospice caregivers' clinical reasoning is to determine whether the delirium might be reversible. The ideal situation is to successfully treat the delirium so that the patient can regain a sense of mental clarity and be afforded more time to spend awake, in coherent interaction with significant others.

Something that can, that may help clear the mind. And I've seen that. I've seen great success with Haldol.

David: Yeah.

To clear the mind, and allow people to have good quality awake time.
Registered nurse

Reversing delirium involves deciphering a possible underlying cause and intervening to correct it. In this setting, reversal generally means rehydration and/or opioid rotation, as these are interventions that can be implemented without making use of medical technologies that are not typically employed here, e.g., blood tests, medical imaging.

We look at the physical symptoms and if we can correct them, uh it's always great. I find that in the last three months of life, which is what we do here, there's often times many things we can do. Uh, you know when they're dehydrated we can rehydrate them, and all of a sudden they're better, they don't have the toxicity of the drugs for example. Or sometimes we're giving the wrong drug and we're getting the side effects of the drugs, we can back off and say let's try this instead. -*Physician*

Often, delirium reversal is not seen to be a realistic or viable goal. In the common scenario of a patient who is thought to be very close to death, delirium is considered an un-modifiable feature of the dying process and the goal becomes strictly about managing distressing symptoms. The palliative interventions in these situations often involve using sedative medications that decrease the patient's level of consciousness. It can be very difficult though for hospice caregivers to know at which point in the dying

trajectory the patient is at, and which avenue, reverse versus palliate only, is most appropriate.

...the challenge is ok, I guess, it's now what do we do? Does this mean it's game over and we have to sedate? And, or do we try and reverse it? –*Nursing leader*

In conversation one evening with a nurse, she reflected her observation that in this setting, various therapies directed at reversing delirious symptoms, such as rehydration and calcium correction, used to be employed more frequently than they are now. Later during our audio-recorded interview, she continued this discussion and offered the following reflection as to the difficulty in deciding whether, as a clinical team, it is best to focus on delirium reversal or symptom management.

...but it's you know, there's a fine line between uh, you know delirium and then terminal delirium, it's, you can't be too, intervene too much if it's a terminal delirium, because you're just going to cause the patient more anxiety and, you know [fluid] overload and congestion and all that stuff, but if it's earlier, it can be, you can see a little turnaround. –*Registered nurse*

The overall emphasis on palliation versus reversal through targeted medicalized management is the result of the cultural environment of the hospice space as largely a non-medical environment, i.e., its identification as *not a hospital*, and also its exclusive focus on caring for patients who are at the very end of life, as opposed for example to patients receiving palliative care but whose life expectancy might be longer than the patients in this setting. In the following interview excerpt, a physician reflects about the uniqueness of the hospice context after having completed palliative care training in acute care institutions.

I realized that [this hospice] is very different from hospital.

David: Hospital palliative care or hospital?

Hospital palliative care. I mean, I've seen two [other] places. But you can see it's, we're much less aggressive here. It's not a hospital, and the mentality of people is much less, 'Let's do this, oh let's do a little blood sample. The patient has a new pain, oh let's do an xray. Let's...' You know? So why do we need to know all this? –*Physician*

While hospice caregivers embrace this non-medical and exclusive end-of-life orientation, they often wonder about whether such a non-invasive approach might cost

them an ability to intervene effectively with respect to delirium reversibility.

...we don't have diagnostic tools to be able to say, 'Oh is it a problem with the calcium? Is there, is this more brain mets?' Like we can't send people down for x-rays, and you can't check for whatever the reasons are that someone can be delirious that could be reversible. We don't have the capabilities here.

David: When you say capabilities, you mean because of where...

Where we are.

David: Right.

Let's say I need to check, in hospital we used to routinely check calcium levels on a lot of patients. Or we would, um, or we might send, send down and check a brain scan. I don't know brain scan, but they might do some kind of x-ray to check for more mets. It's a lot easier to send a urine sample when you're in the hospital, and get a result back within a reasonable period of time. So, some of that is frustrating from the medical point of view, yeah.

David: At the same time, do you think that it was just a matter of logistics? Like if there was a lab in the backyard or, would you be doing all of those things? Or is there a cost to that also?

I don't know, I don't know. I can't answer that because, um, I don't think with the physicians that we currently have, that that would be done ... I'm just saying that in a palliative care environment in a hospital, often we would do that because it was available, why not see if we can change this, kind of thing.

David: Right. And it comes back to maybe what we were talking about mindset, I think when you're in a hospital, there's an overall kind of natural orientation to correct and reverse things.

Right, right

David: Whereas here there's more kind of a bearing witness to deterioration.

Yeah

David: And accepting that the changes that we see are part of the dying process.

Correct. At least that's the way I remember it being. Exactly. That you're in a hospital, if I have the capability to check on a calcium, and in a couple hours the result is back, hell, why not if I can get the blood. Um, because it is a distressing symptom to watch, and to have a family watch, more so than me. Um, so, why

not try and treat it? So I guess there's not, because there's not a step-by-step logical ruling out of x, y, and z, that I myself am a little, I'm wondering if we couldn't do a better job, medically when it comes to delirium. Maybe we could and maybe we couldn't, but I do always question that in my head because of that. –*Nursing leader*

A potential consequence of focusing almost exclusively on comfort and symptom palliation rather than delirium treatment and reversal, according to some hospice caregivers, is that patients end up being sedated too quickly, thus complicating the time dimension (Chapter 5) of good death practice.

D: What would you say is the impact of end of life delirium here?

Um. It can be quite traumatic for the families because um, often people end up being sedated rather quickly and um, and perhaps too quickly. Perhaps um, there, maybe it should be explored if we should use different drugs and not jump so quickly to the Nozinan (sedating anti-psychotic). Because they go from being alert and maybe in a very agitated state, to then being asleep. And so the families may not necessarily have time to say what they wanted to say. –
Registered nurse

Medications and tender loving care.

Medications play a very important role in symptom management and promotion of comfort. Medications are given for pain, shortness of breath, anxiety, nausea, hiccups, as well as manifestations of delirium such as confusion, hallucinations, agitation, and restlessness. In one sense, medications seem to represent the principle and most significant tool at hospice caregivers' disposal in palliating the suffering of dying patients. The availability of medications allows hospice caregivers to take concrete and decisive action in controlling the distressing symptoms that confront them in their work.

...thank God for Haldol and Nozinan, you know. 'Cause it [delirium] can make, it can make the person really uncomfortable and agitated. Which makes the family uncomfortable and agitated, and takes away our concept of good death. So, the docs [physicians] and nurses, and the team, are very sensitive to that issue. And if it's a negative delirium, complete with awful things for the patient, as quick as we can we catch that and medicate it, to make them more comfortable. –*Psychologist*

...sometimes the medication works very well. And it's like, I'm so glad I have the medication. I give [it] to them and they're so much more comfortable.

David: For people who are agitated?

Yeah agitated, delirium. *Nursing assistant*

Interestingly however, while medications are a primary resource to hospice caregivers in facilitating a good death, they are simultaneously considered a relatively minor component of comprehensive palliative care.

Medication is really the smallest, smallest portion of what we do here. –*Patient care attendant*

The major thrust of palliative caregiving, its essence, is about “tender loving care.” It is about creating that environment in which patients and families can feel safe, through the presence and relational engagement that the hospice tries to facilitate.

David: ... what is this place [hospice] all about?

... It’s dying with dignity. [...] We know we won’t give you quantity, we know we’ll give you quality [of life], or we try to.

David: How do you do that?

Um, TLC [tender loving care] I think is the only real way that we can do that. [It’s] 90% of what we do. There is 10% sweat, which is our medication, our recipes. –
Physician

The nursing approach to a patient who is uncomfortable with delirium mirrors the more general approach to comfort offered to all patients. Nurses are sensitive to various bodily disturbances, e.g., full bladder, constipation, that can contribute to discomfort that manifests as mental suffering. Thus, the approach is to perform a complete assessment of any and all potential threats to the patient’s comfort. In the following interview with a nurse, she identifies several sources of discomfort that might cause or contribute to discomfort, “agitation,” in a delirious patient: urinary retention, dehydration, pain, wounds, thrush and sore throat. She explains that the nursing care of a delirious patient toward their good death is about engaging with the “big package” of elements that might undermine comfort (recall the conceptualization of delirium as an embodied experience, Chapter 6), and in response, providing basic nursing care that attends to these elements, all within a guiding framework of “tender

loving care.”

David : ...what about non-pharmacological strategies, are those used also?
Together with the medications or...

Yeah, well I think we need to. Um, retention is a huge, you know.

David: Urinary.

Urinary retention is a huge, you know cause. Or contributing factor towards deli- agitation, delirium. And dehydration. And pain, but that's the medication again, you're getting back to that again. And comfort, just general comfort. You know somebody has a bedsore or anything like that. Or, just bathing a patient. And massage is a really good strategy for comfort and relaxation ... therapeutic touch... you know all those strategies. And mouth care. And if somebody has thrush and sore throat, it's just all such a big package that...

D: So it's basically head to toe, figure out what are the threats to comfort, and intervene there?

Yeah. And intervene. And do your TLC, and just be present with them. –
Registered nurse

While the hospice ethos is about creating a safe place for patients and families, and tender loving care is the primary mechanism by which such places come to be created, delirium poses the unique challenge of forcing hospice caregivers to question the limits to which their tender loving care actually makes a positive difference.

David: From your perspective, what role do medications play in the management, treatment of delirium?

Well I think they play a large, quite a big role, yeah. To ease the symptoms of the delirium. And um, because you can only, if the patient is in active delirium, you can only do so much you know, with bedside TLC. Because that's not going to, it doesn't work.

David: Right

I mean it might work for five minutes. But then you're back in the room in another five minutes, and the patient's again crawling out of bed or whatever. So I think medication plays a huge role. And uh, and it's usually pretty effective, it's pretty effective. Between Nozinan and Haldol. And then, for terminal delirium or agitation, you know the stronger medications like Versed and syringe driver, Nozinan and syringe driver. But those medications work really

well. And they're certainly really important. Yeah really important. –*Registered nurse*

While all of the hospice caregivers I spoke with confirmed the central role medications play in the clinical management of delirium, they also spoke to the variability observed between and amongst themselves in making decisions about how to respond to manifestations of delirium with medication. This is an interesting complication to my observation that all hospice caregivers here share a common mindset, are on the same page, when it comes to good death practice. For example, while nurses generally felt that they had medications available to them to properly care for their delirious patients, this was not always the case.

At change of shift, the nurses are chatting together about Mr. G who died this week. One of the evening nurses relays her experience of caring for this patient while he was delirious. She says that with most of the physicians, there is some “consistency” in how they would manage delirium. However for Mr. G, it took her “a long time” to “get” Nozinan. She describes that Mr. G was “tunneled” (she brings her hands to her forehead and moves them outward to demonstrate a tunnelled thought process) - “you could tell he was not comfortable,” and she moves herself in her chair to illustrate his restlessness. She explains she knew what she needed, i.e., Nozinan, because she has a background of experience to compare this patient to [note: this is one of the nurses who has worked here since the hospice opened]. She worries about newer nurses who will “just go by the doctor’s orders” because they don’t have the same experience or knowledge. –*Fieldnotes*

This nurse “worries” about her nursing colleagues who might not advocate for their patients to receive certain medications that they “need” to palliate their patients’ mental suffering due to delirium. Her concern is reflective of a wider observation that certain hospice caregivers are at times sceptical of each other concerning medication administration. The nurse who lamented in an earlier excerpt that overnight her agitated patient had not received any Haldol is an example of this. Another nurse reflected to me during her interview that nurses’ own uncertainty or unease with medication can be a barrier to the patient receiving what is necessary for them to become comfortable.

Nursing is subjective, as is most things, and it depends on which nurse is on and how they feel.

David: Um hmm.

About the situation, you know. And are they comfortable using medication? There are some people here I know, who I've worked with from the beginning, who are uncomfortable using medication, and they use that as the last resort. –
Registered nurse

Bringing Families on Board

In this setting, hospice caregivers draw on culturally established frameworks for understanding and explaining clinical end-of-life phenomena. Specifically, they tend to share the following assumptions: 1) Death is a natural life event that need not be feared; 2) The alleviation of suffering in dying is a noble and realistic goal; 3) Normal dying occurs through a series of predictable changes; and 4) Bearing witness to these changes facilitates preparation and acceptance of eventual death. Through their experience of attending to the dying of hundreds of patients, hospice caregivers in this setting have developed an intimate familiarity with the dying process. They have been witness to dying in many of its forms: peaceful, anguished, beautiful, ugly, quiet, loud, organized, chaotic. Over time, they have come to believe that some of these forms are better than others. Conversely, families often come to the hospice without any prior experiences with death, or with prior experiences that were traumatic. In the short time available between admission and departure, hospice caregivers attempt to acculturate families to the notion of what a good death can mean, and engage their participation in and support for the necessary action by which that can be achieved.

This section looks more closely at the relationship between hospice caregivers and patients' families. I examine this relationship within the overarching context of creating a safe place for the good death in situations of end-of-life delirium. I suggest that hospice caregivers help families to structure their moral experience in such a way that images and experiences of mental suffering can be integrated into prevailing scripts of what it means to die well. Helping families to structure their moral experience involves offering explanations of illness-in-dying that are commensurate with the good death paradigm. Moral experience here refers to the way that lived encounters are interpreted, specifically the extent to which a person feels that values

he or she deems important are realized or thwarted in everyday life (Hunt & Carnevale, 2011). A moral experience framework is appropriate to considering the family experience of hospice, which may be characterized as “a sense of ambivalence or uncertainty about a lived encounter [whereby] the person identifies the experience as having significance in relation to values that matter for him or her” (p. 660). As described in Chapter 4, hospice caregivers assist families in navigating feelings of ambivalence and uncertainty in relation to their loved one’s dying and also in relation to the care provided. Ultimately, hospice caregivers provide a meaning scaffold through which images and experiences that challenge the good death are positively reframed as morally acceptable. This work is believed to be important in supporting families through the death of their loved one and also to set them up for a healthy bereavement.

This process of structuring moral experience, to successfully offer an interpretation of the dying experience that will be appraised as “good” by family, requires that they be “on the same page” as the hospice caregivers. To be on the same page means holding similar ideas about what normal dying looks like, which provide a frame of reference for coming on board with the priorities and values of hospice toward the facilitation of a good death. Getting families onto that page, or what I am calling “bringing them on board,” is a major thrust of the family work that occurs in this setting.

Offering explanations: what normal dying looks like.

During a loved one’s dying, family members are at risk for being harmed by experiences that they do not fully understand. Hospice caregivers see an important role for themselves in educating and coaching families so that they can integrate what they are witnessing with morally acceptable ideas about what it means to die well. This is part of the work of creating a safe context for dying that is part of the commitment of hospice caregiving (Chapter 4). Hospice caregivers see value in helping families to create images of the dying experience that will stay with them and provide comfort to them in their bereavement. They also attempt to reconfigure disturbing images to minimize the risk of family being haunted by painful memories later on.

There are multiple ways in which the delirium experience can be interpreted and explained. Recall from Chapter 6 that delirium at the end-of-life is sometimes

conceptualized as suffering, but sometimes also as wellness. In some cases, hospice caregivers help families to progress from initial uncertainty and distress over delirious manifestations toward an appreciation of delirium as a positive experience. In the following example, a physician describes framing for family hallucinations of deceased relatives as “beautiful,” “privileged,” and “comforting.”

...some delirium are more specific to these kinds of visions, the death bed visions that are commonly called. And that, I try to reassure the family that this is a very beautiful moment that you are witnessing now. We are very privileged that you can see your loved one not being alone right now...And this is extremely comforting for the family. Family members, when they witness that, are amazed and ecstatic. Because they say, ‘Wow, maybe my mother is with him now,’ or, ‘Maybe my brother came back.’ –*Physician*

Delirium is potentially threatening to the family’s good death because it is one of the changes that happen in the dying process that can produce frightening scenes that are carried forward by family into bereavement. Delirium in dying is also disturbing because the subjective ways in which the patient lives through his or her delirious experience is a mystery. Because of the lack of cognitive access to patients in delirium, explored earlier, families struggle with uncertainty concerning the nature of their loved ones’ lived experiences of comfort or distress. As one daughter of a delirious patient told me, it is “so difficult, not knowing what this is like for them.” Further, as described in Chapter 6, delirium changes the context of interaction between patient and family. During a meeting of the volunteer bereavement support callers that I attended, one support caller talked of explaining to a bereaved family member that, “Sometimes they [dying patients] say things they don’t mean.” During this meeting it was apparent to me that helping family members to integrate images of delirium that occur during a loved one’s dying is a significant aspect of this work. I later followed up on this topic in an interview with one of the coordinators of this program.

David: When we were at the meeting, you mentioned something that stuck with me. You said people will say, ‘I just can’t get that image out of my head.’

Um hmm. Yes.

David: Can you talk to me a little bit about that?

Yeah. And it is the image of their loved one’s final day, or hours, usually. And it

is all the physical changes that, if they haven't seen it before, are alarming. Whether it's the eyes staring, or glassy, whether it's the little tear that may come down their cheek. Whether it's the gurgling, Cheyne-Stokes reactions [breathing pattern changes]. You know fluids [respiratory secretions]. Grasping for something in the air, that they don't understand, 'What are they grasping for?' Um, their voice, the sound of their voice. And uh, confusion. Those are generally the images that people seem to have. –*Volunteer*

Thus, helping families through the experience of a loved one's dying involves anticipating and explaining the various bodily changes that are natural in dying, but that are frightening and disturbing to families for whom such changes are unfamiliar. These changes include but are not limited to manifestations of end-of-life delirium, and all affect the ways in which the dying person's final moments will be remembered. One of the most common questions families ask as their loved ones are dying is 'Can he/she still hear me?' This speaks to the uncertainty families feel concerning the social presence of the dying patient. Similarly, changes referenced by this volunteer such as a changed look in the patient's eye, or the patient becoming confused, affect the patterns of engagement between patient and family and create uncertainty around ideas of social presence. A patient grasping for something in the air might indicate a visual hallucination or might be interpreted as restlessness.

As introduced in Chapter 4, when patients cannot speak for themselves, families observe with great vigilance the moment-to-moment changes in the dying patient. They struggle with uncertainty about the extent to which such changes might indicate that the patient is uncomfortable or in distress. Such uncertainty can result from more dramatic bodily changes, e.g., respiratory congestion that creates an image of "gurgling," which families interpret as meaning that the patient is struggling to breathe, drowning in their own "fluids." Such respiratory changes absolutely undermine the peaceful imagery of the good death. Uncertainty can also result however from changes that are much more subtle. A patient's small movements, e.g., of the fingers or toes, or even briefly opening one's eyes, can cause anxiety for families, who will ask hospice caregivers whether these are signs that the patient is uncomfortable. Repeatedly throughout my fieldwork, families spoke of their need for reassurance and explanation from hospice caregivers about what was "normal" at this stage of life, given their

“knowledge” and “expertise” concerning the intricacies of the dying process.

Dying is, usually, not something that happens all-at-once. Rather, patients are seen to deteriorate along a predictable course as death approaches. As explored in previous sections, the good death seems to be one in which physical and mental decline keep pace with each other, over a gradual though not prolonged period of time. Examples of anticipated decline include reduced ability to mobilize, increased somnolence, and decreased engagement with the outside environment. Some patients however do not follow such a typical course; rather, they are “dying on their feet.” In one way, this is affirming of the good death, where such patients are engaged in life and with those around them right up until their death:

I ask the nurse about this expression, “dying on your feet.” She says that’s literally what it means: it’s when a patient is grey, mottled, short of breath, “All the signs,” but still walking around. And then they just die. She mentions that these are people who probably “struggled for independence,” and die “the way they would have wanted.” –*Fieldnotes*

The difficulty with this trajectory, however, is that it does not provide sufficient opportunity for hospice caregivers to gradually normalize the changes of dying for family, helping them to prepare, little by little, for the patient’s eventual death. In situations where bodily and mental dying seem out of pace with each other, family might have a harder time acknowledging that the patient is deteriorating and will soon die. The concern of hospice caregivers is that in such situations family will experience the eventual death, when it happens, as a devastating shock that they were not prepared for.

I ask another nurse what “dying on his feet” means. She references a patient who just died last evening who fits this idea. These are patients who are still awake, but who from the hospice caregiver perspective “could die at any moment.” She says these patients are, “Still getting up” - “Still going out to smoke.” I ask her if she feels this is a problematic situation. She says it can be, because it makes it harder for the family to “see what we see.” –*Fieldnotes*

When families witness and integrate changes in the patient’s state as consistent with the normal changes of dying, when they “see what we see,” they are observed by hospice caregivers to become more comfortable in the hospice. In the following example, a nurse describes a time interval between a particular patient’s loss of the

ability to eat, and the loss of a “connection” with him through eye contact. This time period was difficult for the hospice caregiver and family relationship, during which each held different opinions around the appropriateness of vain attempts to feed the patient. After loss of a cognitive “connection” to the patient, however, the family perspective appeared to come into line with the hospice caregiver perspective. The nurse believes that this change facilitated a letting go (Chapter 5) of ideas of needing to feed the patient.

In report today we hear of a patient who is dying comfortably. The family has made a complete turn. Their anxiety is way down. Later I ask the nurse what the family was so anxious about. She replies that the wife was intent on feeding the patient. Now she is less so. I ask if this is because of time or coaching, and the nurse says “Both - Lots of explanations.” Apparently the patient required a lot of cuing, and even when cued, wouldn’t really eat. His wife had been “shoveling” the food in. The nurse says that the patient, who has a brain tumour, used to be able to “connect” with you through eye contact, but now there is no longer the same connection. The nurse thinks that this change has contributed to the wife’s understanding that the patient no longer needs to eat.

-Fieldnotes

In conceiving of normal dying as a series of predictable changes, including changes of consciousness and cognition, and in helping families to bear witness to these changes to support their letting go and acknowledgement of impending death, hospice caregivers employ a language that refers to the “little deaths” or the “little goodbyes” in their conceptualizations and conversations with family members. As conveyed in the following excerpt from my interview with a nurse, helping families to see death in this way facilitates a gradual integration of multiple losses as they arise and preparation for the impending final loss, the death of the patient.

Really we lose our loved ones in stages. It’s, death is a series of little goodbyes. There’s a goodbye to your mobility. There’s a goodbye to everything, to wanting to eat, a goodbye to drinking. And then there’s a goodbye to being able to talk, sometimes. And so, and then they see that their loved one is sleeping more. It’s like, they’re seeing these steps. And in some ways, if they’ve been, if there’s been explanation, if there’s been talking and exploring with them, they will actually very naturally themselves start to see it as, see it in those steps. And I think it can help them with the final, the final departure. When the person does physically leave their body, and that’s it. You know? *-Registered nurse*

In this nurse's reflection, the value of bringing families on board is rendered explicit. Through "explanation," "talking," and "exploring," families themselves will begin to see the situation in a similar way as the hospice caregivers. This is important because when families and hospice caregivers share a similar set of assumptions and expectations, when they are on the same page, the work of creating the good death is more seamless. In the following excerpt from an interview with a nurse, she speaks to how the presence of family members who have not reached a place of being "comfortable with the death," undermines good death practice. This is because such families interfere with the ability of the nurse to focus on providing the patient the best palliative care she knows how to provide. In this way then, the value of bringing families on board, both to the reality of impending death as well as to opinions about optimal care strategies, is for the sake of families themselves, but also for the sake of providing for the patient's good death. For this nurse, families who are not "realistic" and do not understand that the nurse is "doing everything" possible to best care for the patient, are "a distraction" to good death practice.

I've had [patients die] without family there, and I've had with family there. And with family there, it's even harder. Because then the family's like, 'Do something! Do something!' And you're trying to do everything you can. And yeah, it's not a good death.

D: So it's worse when the family is there because they kind of witness the suffering, is that?

They witness the suffering, and it's a distraction. You're focused on the patient and caring, like giving the care to the patient. If somebody's not there to witness, you can be focused on giving the patient the best care. The best medication, everything. But when the family's there, you also have to consider their needs. I mean, I've had patients moaning and stuff, and I can handle it. I'm like, 'Ok, you're moaning. I can do this, I can do this, I can do this. But when the family's witnessing, and they're like, 'Oh my God they're moaning, do something!' Then you also have to take care of their needs, and make sure it's not too distressful for them.

D: Ok. And is that harder? To kind of take care of the patient, and take care of the family's needs, all at the same time?

Usually harder, yeah, than not having the family there. Yeah. Well it depends on the family. Some families are really realistic. And they see the suffering, but they

understand that you're doing everything you can do. And they just kind of like, let you take care of them and do everything you can do. And they're not, when they're less distressed, when they're more comfortable with the death, then it's not so bad. But it's when they're uncomfortable and they're not ready.

D: So is it fair to say that, um, it's easier, or things generally work out better, when families are kind of on the same page, or on board?

Absolutely. [laughs] Yep. For sure. –*Nursing assistant*

The process of bringing families on board with the realities of dying happens orally and in writing. Families are given “literature” on the dying process, which consists of four pages of typed text that outlines the various “signs and symptoms” of imminent death. The document is titled “Preparing for approaching death,” and states that it is “a guideline, a road map.” The document presents the various bodily changes in dying as the “normal, natural way in which the body prepares itself to stop” and also is explicit in suggesting to families ways to respond to the person experiencing such changes. For example, with respect to disorientation: “Identify yourself by name before you speak rather than to ask the person to guess who you are.” With respect to restlessness: “Do not interfere with or try to restrain such motions. To have a calming effect, speak in a quiet, natural way.” And with respect to vision-like experiences: “Do not contradict, explain away, belittle or argue about what the person claims to have seen or heard. Just because you cannot see or hear it does not mean it is not real to your loved one. Affirm his or her experience. They are normal and common.”

Reconciling delirium and the good death: a process of normalization.

In Chapter 6 I introduced the idea of delirium-as-change as a way in which hospice caregivers conceptualize end-of-life delirium. As patients die, it is anticipated and accepted that they will be seen to change in the way they relate to others and to the world around them. Patients’ thought processes, as assessed by hospice caregivers through everyday and ordinary interaction with them, appear to slow. It is considered normal, in this setting, for patients to become withdrawn, confused, somnolent, or restless from one moment to the next. These changes are inherent to, and not deviations from, the expected dying trajectory. In the face of such changes, hospice caregivers have a choice. They can react to these conscious and cognitive alterations as

disturbances, or they can weave them into a coherent system of meaning that preserves the integrity of the good death experience.

Families are reassured when they are explained that the changes associated with delirious dying are extremely common. This information reinforces that what is happening is normal, that hospice caregivers know what it is and what it means. The success of offering such reassuring explanations requires that all hospice caregivers agree on the meaning and significance of such alterations in dying, to ensure the consistency of message that will need to be repeated to family if it is to be taken up. As the following nurse explains, the process of offering explanations that reframe upsetting circumstances in dying as 'normal' is not always "heard" by family. Hospice caregivers persevere in their attempts at structuring a positive moral experience through repeating consistent messages. Such repetition represents a "work in progress," whereby "some people need to hear it every day."

Sometimes it's [delirium] just one of those things and it's, it's almost inevitable as a process.

David: Um hmm.

And again, we try and naturalize that here...

David: Oh, with the families you mean?

Yeah, for the families. Um. Yeah.

David: And you find that's successful?

Um, I think it can be. I think it's a work in progress.

David: Um hmm.

And I think sometimes uh, no matter how careful you are, some people need to hear it every day. And some people hear it but don't really hear it. –*Registered nurse*

Offering repeated and consistent explanations to family that normalize the conscious and cognitive changes that are witnessed in delirium is thought to facilitate their letting go of the patient. As described in Chapter 5, facilitating letting go is an important feature of good death practice. The loss of the patient's personality, usual

patterns of interaction, and eventual communication altogether, while painful, are all part of the buildup to the eventual death.

...it's the physical changes. And it may be the change from using the bathroom to the commode, to the Depends [incontinence brief], you know all those physical changes, and delirium's another one that gets people moving toward the okay, this person's changing, and the 'petits morts', the little deaths that that person is having um, are, the person is changing and leaving. You know, and in the big picture that's helpful to the family. Hard at the moment, but...it does help the reality check and get us talking about the elephant in the room again. Yeah, that the brain's letting go. Because each system is letting go. –
Psychologist

Conceiving of delirium as an expected change in dying involves inviting family to externalize responsibility for what is happening. In the following excerpt, a nurse explains the importance of “sitting down” with family to reassure them that they are not to blame for the disturbances witnessed in delirium-as-suffering, nor are such disturbances under the patient's control.

Sometimes we can't make it [delirium] better. Whatever, we pull out every stop, and everything we do sometimes can't help. But comforting the family, and explaining what's going on from our perspective, can help the family's anxiety.

David: So what sorts of things do you do to comfort or to reassure the families?

Well the first thing is, you might take them out of the room. And you sit down and talk to them, and tell them that, try and explain what's happening with their loved one. Um, and try to explain to them that it's not, nothing that they're doing that's for sure. And it's not, sometimes the patient's, it's out of the patient's control. –
Registered nurse

Externalizing responsibility for disturbing delirious behaviours is especially important when the delirious patient is directly hostile toward family members. Such a circumstance is particularly undermining of the good death, which is ultimately about offering the patient and family time and space to come together in positive and health-promoting ways.

Mrs L was crying this morning. She was upset about how her husband had pushed her while delirious. The nursing assistant explained to Mrs. L that her husband is in the process of “detaching.” -*Fieldnotes*

In this brief exchange, the nurse makes use of the conceptualization of delirium-as-

change to normalize the patient's cognitive and behavioural disturbance while externalizing the consequences of this from the patient-family relationship. She provides a context to explain and make sense of the patient's agitated delirium, while attempting to preserve the integrity of Mrs. L's relationship to her husband.

As demonstrated in the above example, patients sometimes exhibit symptoms of delirium that are distressing or frightening to the family. Agitation and combativeness, for example, interfere with the family's opportunity to perform affectionate behaviours toward the patient, and are thus threatening to their moral experience of the dying process. In response, hospice caregivers explain the disturbing behaviour as a function of the illness, as something for which the disease itself is responsible. The purpose of this explanation is to comfort, reassure, and absolve family members of guilt or responsibility for the patient's behaviour. This is particularly relevant when patients with delirium behave in a hurtful way toward their families.

D: What about the families?

...I'd say in the worst case scenario, it [delirium] upsets the family, and they're going, 'What's going on?' You know, 'Why?' Well for one thing, say lung cancer with brain metastases, they don't understand what that means, brain metastases. And so sometimes we do some reframe work from a psychology aspect, and talk about the disease, the rage at the disease has nowhere to go.

D: Sorry, the rage at the disease?

The rage at the disease has nowhere to go. It's so generalized, the anger. So it may come out inappropriately, it seems to the family. But if the person's angry, it doesn't mean they're angry at you, um, 'The Beast' in English, we often call cancer. Or the French, 'Le Monstre.' But I reframe with the family the fact that this is the disease talking. You don't have to personalize this and feel like that's directed at you. And uh, that seems to help a bit, reframe, cognitive work. You know? –*Psychologist*

Another way to minimize the threat of angry delirious communication to family moral experience is to conceptually isolate the patient's behavior from his or her personhood. In the following example, there is a *usefulness* to the idea of social, personal, and/or relational death as preceding bodily death in delirium. Families are encouraged to realize that the person before them, behaving in unsettling and even horrifying ways, is actually *not* their loved one.

Sometimes helping the family to realize that sometimes the delirium, it's the disease the delirium speaking too, and the person has totally changed personality. And in a sense they'll realize they've already suffered the death of the person they knew. Now they're dealing with the disease person ... And yes sometimes it's to give people the space and say yes it's ok to mourn that. And to recognize it. And sometimes too it's helpful, a patient may look at a loved one who they've never said this to, 'Get the fuck out of my face.' I was in the room one time when that happened. And I think, it was the son or daughter, [imitates breaking down], they went running out of the room. They'd never said, like, that to anyone in the family before. So we just gave her some time, and then I went with one of her siblings and we just invited her if she wanted to talk about it. And she said, 'He never said that.' And then she said, 'That's not Dad.' I said, 'Yeah. That's the disease that told you to get the fuck out of his face, that wasn't your Dad.' And she said, 'Do you think?' And I said, 'Well, did he ever treat you that way at all before in your life?' 'Never!' I said, 'Well, look at the disease he has, and how it affects him. It affects, as we know it's metastasized to his brain.' Or he may already have glioblastoma or something. And I said, 'Sometimes, there's a major personality disorder.' And I said, 'The nurses, the doctors, have talked to you about this. And sometimes it affects our personality as well. And whether he knows he's saying it or not, we don't know.' But I said, 'If you say that wasn't your Dad, then you know it wasn't in your heart.' You know so, you just try and help people realize that sometimes disease will do things. And it's not necessarily the same person that we've loved. It's almost like a Jekyll and Hyde thing that we're talking about. And so that's all you can do. All you can do is offer them that. Yeah. And what they do with it in the long run, obviously they need to integrate that. -*Volunteer pastoral care provider*

Further, as part of helping families to structure a moral experience in which manifestations of delirium are removed from the patient-family relationship, hospice caregivers give "permission" for family members to take leave from the situation.

Mrs. P is "climbing out of bed," "restless" and was "aggressive with her daughter." The nurse says her daughter was "almost in tears" and was trying to reason with her mother, the patient. Mrs. P is saying she wants to get out of here, wants to go shopping, and her daughter is replying to her that she's here because she's "sick." The nurse tells us that she explained to the daughter not to take it personally, and also encouraged her to take some time away, both in the moment, "Leave the room if she talks to you like that," and for a day, "You're here everyday, it's ok to not come in one day." "I give you permission," she told her. -*Fieldnotes*

While offering explanations that rely on understanding the dying delirious patient as absent, missing, or already dead serves some purpose as described above, this interpretation can be somewhat misleading, in that it may obscure the reverence and

respect for the life of the delirious patient that hospice caregivers promote. While they may, for the sake of family wellbeing, offer explanations that deny the patient's social identity, they are at the same time affirming the identity of the patient as an existential being whose life's value is unaffected by delirium. As described in the following excerpt from an interview with a nurse, showing families that they care in this way is believed to be reassuring and helpful. In this way hospice caregivers role model a new way of being toward the patient so that family members can still be present to their loved one without interacting with them in ways that prove distressing and uncomfortable.

And uh, when you can show that you're caring for a person by the thoughtfulness of how you do the care, that you're still speaking to the patient, that you're still being very considerate of how you do it, that's also very reassuring for the family too. And it helps them know that they can still hold their loved ones hand, they can still be present, they may not want to stimulate their patient or wake them up, sometimes that's a hard thing to teach, because the family, they're grieving that they're losing, if the patient is going to sleep now more, they have a hard time sometimes losing the patient's awakensess. And yet, they also realize, well when my loved one's awake he's totally confused, and that's no good either. And so it's teaching them how they can be present still to their loved one, even though their loved one can't talk back anymore. –*Registered nurse*

Finally, normalizing conscious and cognitive changes in dying invites families to let go of misgivings they hold about the care being provided by hospice caregivers. Specifically, such misgivings generally have to do with medications that are being administered to promote comfort and alleviate distressing symptoms, but that can also cause delirium, e.g., opioids. It is extremely common for families, when confronted with a change in the patient's mental status, to attribute the cause to medication.

Hospice caregivers will readily attempt opioid rotation in patients who are otherwise stable and whose mental status changes do not seem to be a consequence of imminent dying. As patients deteriorate and time before death grows ever shorter however, tinkering with medications poses too great a risk to the patient's comfort. Medications that are used for pain or other distressing symptoms are considered necessary, and opioid rotation in a patient very close to death would risk causing the patient pain during their dying moments. According to one physician,

...most of the medication they receive, they need to receive it. *Physician*

Understanding mental status changes as resulting from medications is therefore an unhelpful interpretation because the risk of changing medications is thought to outweigh the potential benefit, and because it undermines family's trust in hospice care. In essence, the interpretation of mental status change resulting from medication is an obstacle in navigating the road to the good death. Focusing on trying to reverse what is happening would mean forsaking the opportunity to support family in getting them to grasp and accept the bigger picture, that the patient is now dying very soon. Again, hospice caregivers strive to provide to families a consistent message that preserves the family's trust in the care being delivered.

There's a lack of knowledge there. A lack of understanding of, of um, the changes that, that are a normal process...[you explain] these cognitive changes...we really don't believe it can be related to these medications, that it's probably more likely to do with x, y or z...Usually you have to repeat it. And often it's on several shifts...And generally people are giving the same message...So that's helpful to the families. They hear it enough times. Okay, it's not just this one person telling me this...This really is what's happening." –*Registered nurse*

This idea, that hospice caregivers "believe" that medications cannot solely account for the cognitive changes observed, is genuine. Helping family members to apprehend that what is happening is a function of dying and not of hospice intervention is, to them, being honest with themselves and with family about their own knowledge of the dying process.

I've seen people change without medication, I've seen people honestly start sleeping more and more and more, without starting a syringe driver for example. So when I see a family attributing sleeping due to a syringe driver, I can honestly say that I've seen somebody come in here and start sleeping more and more without a syringe driver. –*Nursing assistant*

Unfortunately, some families never come on board with the explanation that delirious manifestations are unrelated to medications administered. In the following example, I spoke with the daughter of a patient who, days earlier, had experienced an agitated delirium, which she believed might have been caused by a dose of morphine that her father had not needed. In her conversation with me, she referred to hospice caregivers offering an interpretation of delirium that is normalizing, i.e., "the transition." While she clearly heard this explanation, she was not entirely convinced.

Ms. D (daughter of Mr. P) spoke of her uncertainty surrounding the meaning of her father's agitation. Was it pain? Was it "Dad escaping the medication? Maybe he didn't want the medication..." This prompted D. to discuss her ambivalent feelings around morphine. She began this discussion with "I'll be frank with you" and then talked about how she and her family worried that her father hadn't needed morphine on Tuesday, and giving this to him is what caused the agitation and subsequent deterioration (he is now unconscious). She tells me that in response to these concerns, hospice caregivers explained to her that the onset of her father's delirious behavior was part of "the transition."

The following evening, I spoke with another daughter of this same patient, Ms. C:

Ms. C tells me a similar story to the one her sister told me last evening, although she is much clearer about her ambivalence regarding the way the dying trajectory and clinical management have unfolded.

From her perspective, on Monday her father was communicating meaningfully and intelligently. They had a party for his wedding anniversary, during which he ate well and drank a few sips of wine.

Tuesday, he had some pain in his back for which he received morphine. That evening, he became restless and agitated. As his agitation continued he was given more medication (it was Methotrimeprazine (a sedating antipsychotic) – but she didn't seem to know this). Ms C. tells me that her father's continued agitation throughout the evening seemed to her to be him "pushing the medication away" because, "he knew it would make him sleepy."

Overall, Ms C. says she knew "this" is where they were heading, i.e., "comatose," "dying," but it was "too fast," and she feels it was "accelerated." She uses this last word several times.

I asked if she had addressed her concerns, questions, and perceptions with hospice caregivers. She says she sort of did with the physician, and feels she was told that she is in "denial." She then reflected on this and said to me, "I don't think I'm in denial, it was just too fast."

Throughout our interaction, she repeats several times that it was her father's first complaint of pain, he received morphine, became agitated, "And then we lost him." –*Fieldnotes*

In this example, there has been a breakdown of trust in the hospice caregiver and family relationship. This daughter interprets her father's delirium as a direct result of morphine, and because this was his last moment of wakefulness, she conceives of having "lost" her father following the administration of this medication. Again, the dimension of time is clearly important to the shaping of the good death, where in this

case the abrupt nature of the patient's change in status is threatening to this family's moral experience. It is also important to highlight the meaning of the patient's delirious behaviour as inferred by family. Recall that in Chapter 6 I analyzed delirium as a relational experience by exploring the ways in which delirious manifestations affected the context of interaction between patient, family, and care providers. In this example, the patient's daughter interprets her father's agitation as a struggle *against* hospice caregivers. She wonders if he was trying to "push away" medications that he did not want. Based on my many months of engaging with hospice caregivers and observing them in their interactions with family members, I would be very surprised if the physician referred to in this example actually used the word "denial" in her conversation with this daughter. What is important, however, is that whether this word was used or not, this is what the daughter *heard*, i.e., it is how she interpreted the exchange with hospice caregivers whose understanding and explanations were very different from her own. I see in this example a powerful instance of the good death undone. For this family, hospice was not experienced as the safe place that it endeavours to be.

A tension is apparent between values of person-centered care that are important to these hospice caregivers, and the arguably paternalistic approach of attempting to structure another's moral experience. Consideration of this tension forces the question: Whose house is this? On the one hand, the hospice was created to enable patients and families to genuinely feel at home - to provide a place for them to truly live together until patient death. In this view, families are encouraged to make use of the space in whatever ways work best for them. They are encouraged to participate in the patient's care to the extent that they desire. Hospice caregivers are also very mindful and reflective of their *own place* in another family's experience, and are careful to not overstep their role.

My role for the family will always be nothing more than a support. Because usually the situation unfolds, and brings out whatever is necessary to allow these families to get there. How they deal with it on a daily basis is then a different issue and that's what I'm there for. I just try and be a listener. Be a support. Be um, a sounding board if that's what they need. Uh, I try not to, opinion, put my opinion on it. *-Registered nurse*

I think it's really important that we don't judge families too much. You know I think that's a very easy thing to do.

David: To judge them?

To judge them. And feel that everybody should fit into this little you know, a mold and this is the way it should be and this is the way they should be reacting...I think we really need to allow families to be who they are. –
Registered nurse

The ways in which hospice caregiver - family relationships develop and play out in this setting are, however, more complex than merely inviting families to be who they are. As Davies (2006) has noted, "Palliative care programs are based on the principle that the family is the unit of care. In practice, however, the family is often viewed as a group of individuals who can either prove helpful or resist efforts to deliver care" (p. 545). In the following reflection by a nursing leader, she suggests the importance of accepting families whose beliefs and values differ from those of hospice caregivers, though also speaks to how working with such families is "more labour intensive."

Well the other philosophical value if you want that we ascribe to is to respect all peoples beliefs and values and things like that. So if it's different than mine, does that mean that it's worse than mine? Well not really. It just means that we need to work a little harder, to perhaps achieve patient comfort. Or it means we have to explain to family, take a little bit more time to explain to family what it is. So I think it's not that it's harder, it's just more labour intensive. –*Nursing leader*

Summary

This chapter has considered the ways in which hospice caregivers engage with manifestations of delirium as they strive to promote good deaths. Processes of relational engagement with patients inform continuous team communication that enables knowing the patient and therefore being able to infer their mental state. Hospice caregivers often balance their certainty that mental state is at issue for a particular patient with their uncertainty over precisely what is going on and the nature of the patient's subjective experience. When confronted with manifestations of delirium and potential mental suffering, hospice caregivers search for the meaning behind the patient's delirious manifestations. This is an effort to connect with them and foster their mental wellbeing. Dimensions of mental state assessment include

disorientation, inappropriate communication and behaviour, and hallucinations. Hospice caregivers make use of a common sense language to understand and communicate the mental state of their patients. When delirium occurs, there is a tension between attempting to reverse it and focusing strictly on palliating distressing symptoms. When attempting to palliate delirium that is distressing, hospice caregivers integrate administration of medications with tender loving care. Medications are primary and necessary, however there are tensions discernible in the practice of administering medications for delirium. Certain caregivers seem more prone to give medications than others. Administration of medications to palliate delirium often leads to sedation, which can itself be problematic for good death practice.

This chapter has also explored how hospice caregivers are actively involved in helping family to structure their experience in such a way that they hope will prove helpful to them in the long run. When manifestations of delirium threaten the family's moral experience of dying well, hospice caregivers offer specific and consistent explanations that normalize cognitive change as part of the dying process and externalize disturbing patient behaviour from the patient-family relationship. These actions are thought to be important to supporting the family in achieving their own good death experiences and setting them up for healthy bereavement.

Chapter 8: Discussion

Introduction

The research question guiding this study was *What is the relationship between end-of-life delirium and the good death in hospice care?* Answering this question required an in depth examination of the culture of hospice caregiving. This meant questioning the meanings that ideas of good death and delirium hold for hospice caregivers, and exploring how such meanings reciprocally relate to each other in diverse ways.

An ethnographic approach to nursing research can illuminate the beliefs, values, and motivations regarding a good death for people local to a specific community or culture (Chan et al., 2009; Wilson, Fillion, et al., 2009). The culture examined in this study referred to a local caregiving community organized within a freestanding residential palliative care facility, a hospice. The methods of this examination took the form of observing and talking with the people who inhabit the hospice while providing or receiving EOLC. I also paid attention to various sources of material evidence (documents and artifacts) to further understand the ways in which caregiving practices are developed and enacted, and the impact these have for all concerned.

For this study I solicited the perspectives of hospice caregivers, patients, and families, and observed caregiving practice over a prolonged period and across a variety of circumstances. Therefore, multiple voices and standpoints have contributed to an overall understanding that is layered in complexity. Throughout processes of fieldwork, data analysis, and the writing of this ethnography, I struggled to articulate a narrative that would be meaningfully coherent but also faithfully representative of the multiple realities and inherent tensions of lived social and cultural experience within the hospice environment. I take guidance from Russell and Gregory (2003) who argue that good qualitative research is messy. According to these authors, good research raises as many questions as it purports to answer, and readers should be dubious of interpretations that seamlessly homogenize into neat and tidy conclusions.

There are several tensions apparent in reading the findings of this study. For example, I reported that a cultural belief of hospice caregivers is that death is normal

and need not be a fearful experience, and yet I also observed caregivers to engage with and normalize patients' fears of their own dying. I described how hospice caregivers resist labeling patients as delirious in an apparent effort to avoid medicalization of the dying process, but also how they advocate for proper identification of delirium to mobilize more effective palliative care. I explored the paradox of cognitive access, whereby in spite of the difficulties to comprehensible dialogue that delirious manifestations pose, caregiver responses to cognitive and perceptual disturbance are largely determined by soliciting the patient's own perspective about whether these are a source of distress. I found that hospice caregivers work toward the good death by bringing families on board with their own established priorities and values, and yet also found them to enact an individualized and person-focused care ethic that operated on a case by case basis and that recognized the unique individuality of all families receiving EOLC. In this setting, the individuality of patient-family experience is honoured and respected - good deaths are as individual as those who die - and yet there are certain scripts for better dying that are explicitly conveyed and encouraged to support people in ways that are presumed will be most helpful to them.

My goal here is not to smooth over tensions such as these but rather to make them explicit in analyzing the diverse realities that appear characteristic of hospice caregiving practice. This approach is consistent with a constructivist perspective, in which single explanations for complex phenomena are neither possible nor desirable. Rather, by developing multiple interpretations about the studied phenomena, seemingly contradictory ideas are brought forth and provide for a more realistic, relevant, and ultimately useful portrayal of the culture studied (Appleton & King, 1997).

Recall from Chapter 3 that I employed relational ethics as a guiding theoretical lens for my fieldwork and data analysis (Bergum, 2013; Bergum & Dossetor, 2005). Use of this framework meant questioning the ways in which relationships are lived in this hospice, seeking to understand: What is the nature of the caregiver – patient and caregiver – family relationship here? How do the relationships that are formed enable or constrain the ability to provide for a good death? In what ways does delirium affect the various relationships at stake? To briefly recapitulate some of the main findings of

this study, I found that in this setting:

- The cultural community of hospice is oriented explicitly toward the promotion of good deaths for terminally ill patients and their families. Working toward the good death is an action-guiding ethic. It sets the standards to which hospice caregivers hold themselves accountable, and shapes the ways in which hospice caregivers relate to patients and families in their care.
- Hospice caregivers conceptualize delirium in diverse ways. Delirium can be an experience of suffering, but can also be an experience of wellbeing. The central question is not whether a particular patient “has” delirium, but whether they are distressed or comforted by changes of consciousness, cognition, or perception in dying.
- Providing for the good death when delirium is a potential issue involves knowing and engaging with the patient’s mental state, i.e., the degree to which the patient is experiencing mental suffering or mental wellbeing. This ‘knowing’ happens through continuous processes of relational engagement with the patient and family, and team communication. Hospice caregivers adopt a purposefully vague and common sense language in their clinical reasoning around patient’s mental state. They balance certainty that mental state is at issue with acknowledged uncertainty over the exact nature of what the patient is experiencing.
- The conceptualization of delirium-as-change provides hospice caregivers with a framework to normalize for families the conscious and cognitive changes that occur in dying, facilitating their letting go and preparation for death.

In the sections that follow, I discuss five salient themes that appear to me to characterize the findings of this study: 1) Hospice as a safe place for dying; 2) Hospice nursing as providing basic but exemplary care; 3) The road to the good death; 4) Relationships with family; and 5) Mind-body dualism. Relational ethics considers “the kind of relationships that allow for the flourishing of good” (Bergum, 2004, p. 487). In integrating the insights developed in this study with ideas from other literature, the discussion that follows contributes to the discourse of relational ethics for nursing by examining the kind of relationships that operate in the hospice setting, and the ways in which such relationships contribute to the co-authoring of an ethical story that

envisions the good (Abma, 2005; Gadow, 1999; Hess, 2003) in situations of dying and of delirium.

A Safe Place for Dying

In a European study that involved interviews with 100 patients admitted to a palliative care setting about their experience of transition toward end-of-life, Larkin, Dierckx de Casterle, and Schotsmans (2007) describe the case of Elizabeth, a 58 year old woman dying of brain cancer. Elizabeth describes the following about her experience of hospice:

Being here [hospice]...has made me generally a lot calmer. It gives you strength and I'm at a kind of, underpinned by it...and I said to [my parents], 'you do realise this is where I'm going to stay to die', and I said, 'it's important because I know I'll be looked after and I know you'll be looked after as well'. And that is important because they will be. (p. 90)

Later in the manuscript, the authors return to Elizabeth's interview:

Interviewer: If I asked you what [name of hospice] can give you at this moment in time, what would you say?

Elizabeth: Safety. A feeling that I can die and it's OK. Safe to die and all the people will look after me and it's not an embarrassing thing. I don't have to apologise. I don't have to pretend. (p. 91)

In these two passages a few ideas are apparent that resonate with my portrayal of hospice in this ethnography. Specifically, the first excerpt confirms the focus of attention in hospice care as providing strength to patients and to families through proper care and attention, referred to here as *looking after*. Elizabeth's acknowledgement of and apparent calm serenity toward her own dying, that it is not something for which she need apologize or pretend, reflect a value of hospice culture that dying is natural and does not have to be frightening. In the second excerpt, when asked what the hospice can provide for her, she immediately uses the word *safety*, which the authors interpret as an "achievement of ontological security" (p. 91).

On several occasions in the findings chapters of this thesis I referred to an overarching ethos of hospice care as providing patients and families with a *safe place for dying*. In this section, I will discuss in more detail what I mean by safety. I draw on previous nursing research studies about EOLC to illustrate the relevance that this notion of safety has for my understanding of what the good death means in a palliative

care context.

Bruce et al. (2011) conducted a grounded theory study of the process of engaging with suffering at the end of life, soliciting the perspectives of patients, families, and health care providers. Participants in this study identified suffering as part of what it means to be human, “to be fully human means to suffer” (p. 7). In end of life situations, however, suffering takes on a new dimension whereby confronting one’s own death or the death of another can result in “being shaken to the core” (p. 7). This was described using the metaphor of *groundlessness*, in which people lose their bearings and their connections that are needed to navigate their world. They become “undone, unravelled, or unhinged” (p. 8). These authors therefore theorize that the basic social process of engaging with suffering at the end of life is *longing for ground in a ground(less) world*, where longing for ground is an active seeking of peace and stability in the face of suffering. This is suggested to happen by way of three processes: 1) engaging groundlessness, 2) taking refuge in the habitual, and 3) living in-between. For participants in Bruce et al.’s study, engaging groundlessness is a process of renegotiating what is normal, acknowledging loss, learning how to let go, and living with what is now. Taking refuge in the habitual, by contrast, is a turning away from groundlessness. It is relating with and holding onto past ideas about self and the world that preceded the current circumstance. Therefore while engaging groundlessness is about acknowledging the present and letting go of the past, taking refuge in the habitual is about “seeking security in the familiar” (p. 12). Bruce et al. described that these two processes, turning toward and turning away from suffering, while somewhat oppositional, are not mutually exclusive. Rather, the third process of living in-between reflects that people actively “negotiate the ambiguities” (p. 14) of letting go while holding on.

My interpretation of hospice caregiving practice resonates strongly with the ways in which people in Bruce et al.’s (2011) study sought peace and stability in the face of suffering. Hospice caregivers enact specific strategies that help patients and families to *engage groundlessness*. They make themselves readily available and position themselves as sources of listening and support as people work through impending death. They invite and validate expressions by patients and families about the many

losses they have experienced and are continuing to experience. Further, they are not just responsive but also proactive in encouraging patients and families to engage with their situation. This is apparent through practices of explicitly suggesting ways that patients and families might say goodbye to each other, put their affairs in order, and begin to make advance funeral arrangements. At the same time, hospice caregivers help patients and families to *take refuge in the habitual* by giving them a space to be who they are, and assisting them to spend their remaining time in whatever ways will be most beneficial to them. Patients and families here are empowered to maintain practices and routines that are familiar and important to them. This might mean leaving the hospice to attend a child's soccer game, setting up a baby's crib next to the hospice bed so that a new family can all sleep together, or hosting a dinner party in the hospice's dining room for extended family and friends in celebration of an important birthday. Hospice caregivers thus facilitate a *living in-between*. They encourage patients and families to take things "one day at a time" and to derive pleasure and satisfaction from each day. Simultaneously, they support an orientation toward the future. Hospice caregiving practice appears to help people to find a way of "living in the flux of knowing that in many ways things are profoundly changing, yet at the same time they are not" (p. 15). In these ways, then, I suggest that the meaning of this hospice as a safe place for dying is about providing much needed *ground* for patients and families as they live through their own end of life circumstances.

Other palliative care nursing studies emphasize important links between a supportive care environment and feeling *safe* at the end of life. Gourdji, McVey, and Purden (2009) conducted a qualitative descriptive study about perspectives of a quality end of life with ten advanced cancer patients receiving care on a hospital palliative care unit. For these participants, their experience of the care environment was hugely determinant for a quality end of life. Through warmth and tenderness, they felt well cared for and cared about by professional caregivers. Further, participants had confidence in their professional caregivers. They felt comfortable in their physical surroundings and trusted in the team's ability and motivation to properly attend to their needs. The study authors likened the construct of a quality end of life to a good death, suggesting that both notions refer to the potential inherent within all people,

when provided with proper care and support, for healthy living even in the face of difficult or tragic circumstances. The researchers interpreted that their participants' experiences of living in a palliative care environment showed that:

Despite increasing limitations, they [patients] remained engaged in some aspect of their normal activities, and this allowed them to maintain their quality of life. A sense of purpose, of reciprocity, of involvement in the day-to-day brought structure to participants' lives; it provided them with comfort and *security*, preserved their identity, and kept them connected with life and the living. Living in a caring environment enabled participants to have quality of life within the context of their illness life. (p. 47, emphasis added)

Seymour et al. (2003) conducted a synthesis of three qualitative studies about patients' experiences of specialist palliative care in the United Kingdom. These authors found that a notable aspect of participants' accounts in two of these three studies was their perception of intimate relating with professional and volunteer caregivers. Intimacy in these contexts meant "chatting" and "having a laugh" during ordinary interaction, as well as having deeper and more meaningful conversations that were initiated by caregivers about patients' problems and needs. For patients, this perceived sense of intimacy made them feel "supported and secure" (p. 30). Interestingly, in one of these two studies the palliative service in question was "based in a building that is informal and comfortable, and which reflects its philosophy of being a 'home from home'" (p. 27). In that particular setting, a sense of "shared humanity" (p. 29) amongst caregivers and care recipients was evident from the data, such that "sharing sorrows, concerns, and even joys and triumphs provided a great deal of comfort" (p. 27).

Wilson, Fillion, et al. (2009) conducted an ethnographic study into the meanings of a good death for rural Albertans. Participants valued receiving EOLC and dying in their home communities. Conversely, to be "displaced" (p. 24) to a city for EOLC threatened ideas of a good death, where displacement meant being removed from loved ones and other community connections. The nature of this threat stemmed from fears of receiving depersonalized care, where in an urban setting participants are "removed from all that [is] familiar" and receive care from "strangers in a busy hospital where everyone is just a number" (p. 24). Depersonalized EOLC was felt to be lacking in compassion and understanding, and therefore failing to provide for a "dignified" (p. 26)

death. Participants also feared for their security if displaced to a city for care. They anticipated a higher likelihood of medical errors in a context where caregivers do not *know* the patient.

The hospice examined in my study is a care institution. Patients who die here are, effectively, “displaced” from their own homes. What is interesting about this hospice however, is the explicit recognition by caregivers of this displacement and their resultant attempts to compensate for this by ensuring that the hospice is experienced as a safe place. In this way, the care offered here anticipates and responds to the threat of displacement for the good death. Practices such as interacting with patients using their first names, welcoming family members at all hours, and planning and delivering all care (assessments and interventions) with no more fundamental reference than the basic question, “How is the patient doing today?” all serve to create a care environment that reflects and responds to the important values of familiarity and being known at the end of life.

Together, findings from the studies just reviewed expound the important notions of *space and place* for the good death. They elucidate the fundamental link between integrity of the care provider-recipient relationship and feeling safe (comfortable, supported, and secure) within the spaces and places where palliative care is provided. They suggest that, like with this ethnography, feeling safe is fostered not only by individual, one-to-one relationships, but through a wider cultural value that seeks to reflect the intimacy of a home space. Indeed, home spaces epitomize a sense of belonging and are therefore beneficial to wellbeing at all stages of life (Carolan, Andrews, & Hodnett, 2006). Increasingly, there is growing recognition that feeling *at home* is less dependent on a literal meaning of home as one’s regular dwelling to a recognition that “one can feel at home in different ways in different places” (Gillsjo & Schwartz-Barcott, 2011, p. 10). For this hospice, the meaning of home space is one in which physical (architectural) and social (interpersonal) landscapes coalesce to produce an overall atmosphere that is liveable. Conceptualizing the institutional care setting as a home space, by essentially recognizing that this is where patients and families *live*, has important implications for the ways that nurses support, relate to, and foster wellbeing amongst those they care for (Gilmour, 2006). Feeling safe within one’s

own space is important for wellbeing at the end of life, as patients contend with the fragility and impermanence of their own lives (Larkin et al., 2007).

My analysis of hospice care as being oriented toward providing a safe place for dying has important implications for interpreting the care of delirious patients and their families in this setting. The findings of this study show that cognitive disturbance in dying potentially transports the patient to a new metaphorical *place*. Delirious patients were often characterized by hospice caregivers and by family members as “not with the world.” The priority question in caring for these patients was about assessing whether this new place is habitable (safe) or a source of distress. In essence, it was about ascertaining the extent to which patients in delirium felt at home within themselves. Sometimes, hospice caregivers might wonder about whether conscious *unawareness*, of circumstance and/or of self, might serve a protective function. It was hypothesized that these patients might be spared the painful experience of confronting the reality of their own dying and/or the indignity of their bodily deterioration, experiences that are commonly a source of existential angst and distress for many patients. In other situations, delirium was conceptualized as “wellness” by hospice caregivers, insofar as the manifestations witnessed did not appear to undermine patient wellbeing, and sometimes even seemed to foster it. This typically occurred when patients revelled in a conscious awareness of people, places, or times that did not reflect the reality of others but that brought comfort and happiness, e.g., a welcome hallucination of a dead relative. While this conceptualization, “as wellness,” is virtually nonexistent within the delirium clinical literature, related constructs such as “nearing-death awareness” (Callanan & Kelley, 1992; Kessler, 2010) and “deathbed phenomena” (Brayne, Farnham, & Fenwick, 2006; Brayne, Lovelace, & Fenwick, 2008) have emerged to describe and interpret cognitive and perceptual changes experienced in dying that are positive and meaningful. These experiences typically involve the dying patient speaking about getting ready for a “trip” and/or having a comforting vision of a deceased relative who is here to accompany and prepare the patient for his or her own death. Interestingly, this literature goes to great length to distinguish itself, conceptually, from end-of-life delirium. Callanan and Kelley (1992), for example, were concerned that the delirium label in situations of nearing-death awareness resulted in

missed opportunities to connect with what the patient was experiencing and what that experience might be telling us about what that patient needed for a peaceful death. In Brayne et al.'s (2006) interview study with palliative caregivers (mostly nurses and doctors), participants distinguished between delirious hallucinations and deathbed phenomena, where the latter held "some kind of profound meaning for the patient" (p. 19). Thus, it appears that the common understanding of delirium as a pathological feature of the dying process accounts for some resistance in conceptualizing positive and meaningful cognitive changes within a delirium framework. In observing the practice of hospice caregivers in this study, however, I found it was impossible to clearly distinguish between their conceptualizations of delirium and care of delirious patients from other conceptualizations such as nearing death awareness that are also relevant here. Recall, for example, the physician who spoke of some types of delirium as "more specific to these kinds of visions, the death bed visions." This participant described this type of delirium as an opportunity for providing reassurance and comfort to families by explaining to them how "privileged" we are to be witnessing the patient having this positive experience.

In contrast to conceptualizations of delirium as wellness, the good death was threatened when patients seemed to occupy a cognitive place that was fear or anxiety provoking, for example patients who felt vulnerable to persecution, attack, or even being killed by those around them. Other patients appeared to lose all sense of place in their delirium, experiencing profound disorientation. When the places inhabited by delirious patients were a source of distress, caregivers sometimes attempted reassurance through reorientation. Other times, the approach might involve attempting to meet the patient where they are, cognitively, and offering reassurance there. Recall for example, the patient who seemed to be reliving traumatic wartime experiences, and her daughter's response of assuring her mother that she was right there with her, and they would face these challenges together.

An important implication of the idea of conceiving of delirium as transporting the patient to a different cognitive place is that in such cases, connecting with that patient becomes more difficult. According to Belanger and Ducharme (2011), who reviewed the qualitative literature examining nurses' perspectives about caring for patients with

delirium, nurses experience these patients as becoming “strangers who [are] in a separate world and whose reactions [are] unpredictable” (p. 311). In this hospice, the idea of building connection with patients to foster their dignity through relationship and therefore to provide for a good death repeatedly resounded as a fundamental feature of the hospice caregiver’s role. Connection is crucial for creating the safe place required for a good death, where safe places are created and maintained through intimate relationships as described above. Further, lack of connection severely limits a nurse’s ability to provide effective palliative care across multiple dimensions of wellbeing. For example, nurses in this study described the difficulties they face in arriving at confident assessments surrounding pain and other symptoms, as well as difficulties in implementing basic nursing care when there is no connection with the patient. Recall, for example, the patient who was both delirious and in pain, and for whom the encounter with the nurse around his dressing change was lived as “you’re hurting me, you just want to hurt me more.”

Notions of place and of the hospice as a safe context for dying are also useful for understanding the implications of delirious dying for family experience. When patients exhibit signs of restlessness and agitation, this can render the space around them as uninhabitable for families, and thus represents another way in which feelings of safety are threatened. Recall the dying patient’s wife who told her nurse that she would not be able to “live through” another night like the last, in which her husband was agitated and restless. She was therefore relieved that he was now asleep (sedated) and appeared to her to be at peace and comfortable.

Hospice Nursing: Providing Basic and Exemplary Care

Throughout fieldwork, I was struck by the ways in which “basic” nursing care was organized and delivered in this hospice. Nurses were proud of the basic care that they provided. Further, a high standard was set by the team such that every individual nurse was held to account for the quality of basic care that she delivered in any given shift. The idea that palliative care nursing is fundamentally about providing good basic nursing is not new. Florence Wald, a nurse and one of the originators of the hospice movement in the United States, is remembered as advocating that, “hospice care is the epitome of good nursing” (Lynch et al., 2011, p. 108). The alleviation of suffering and

the promotion of dignity, a moral engagement to which palliative nurses are above all else committed, are fundamental responsibilities expected of all nurses regardless of practice context (CNA, 2008a). In palliative care contexts however, these commitments move to the fore as other competing nursing commitments (e.g., keeping the patient alive through high technology care) are no longer relevant (Scott, 2005).

That hospice nurses successfully focus on the basic comfort of their patients and families is a function of the overarching value system that defines hospice culture. According to a British study of hospice nursing by Evans and Hallett (2007), nurses' enactment of a basic caregiving ethic takes time and attention, and is made possible "due to an environment in which a palliative ideology grants 'permission' to spend time in comfort work" (p. 749). Such a palliative ideology equally predominated in the hospice I studied, such that nurses were "free" and "expected" to provide their patients and families with basic care, and to form therapeutic relationships with them in the process. The importance of the influence that unit culture plays here needs to be emphasized. When care providers work within an environment that does *not* support an ethos to end-of-life caregiving that is underpinned by a commitment to excellence in basic palliative care, caregivers are severely limited in their ability to support dying patients and their families in helpful ways (Casey et al., 2011).

The significance of providing for basic needs when nursing patients with delirium has been highlighted in other literature. Wilson et al. (2010) for example highlight that such care activities are not only about providing for patient comfort, they are also a means of *safeguarding* the patient's wellbeing. They write that:

Basic care activities by nurses, such as ensuring beds are dry and comfortable, or by addressing nutrition and hydration needs, are not just undertaken to ensure patient comfort. These activities reveal a holistic approach by nurses to safeguarding patients. Patients who are experiencing acute delirium are at high risk of pressure sores, malnutrition, dehydration, and other complications. This basic care nursing practice [shows] that nurses have knowledge and skills that they appreciate as being valuable to patients." (p. 85).

The word "basic" in describing the comfort giving and safety promoting actions in hospice care is perhaps misleading. I use this descriptor because it appropriately refers to foundational ideas of what good nursing is all about. It refers to the care practices

and philosophies that are first learned in nursing school (e.g., assistance with activities of daily living, listening to the patient and family). Hospice nurses told me that it is an orientation toward these activities that sustain them in their practice, because their propensity for providing such “basic” care was the reason they originally chose nursing as a career. It is important to note, however, that “basic” in this context does not mean simple, easy, or less-than something else more complex. To properly and faithfully enact “basic” care in this context requires more than technical competence. It requires also a recognition of the moral implications that such caregiving acts have for the experience of achieving a good death at the end of life. This distinction may seem subtle but it is important. An example will help make this point. Perry (1998), in her participant observation study of what she calls instances of *exemplary* nursing care, describes a nurse who decides to withhold an oral medication from a patient very near the end of life. For this nurse, her decision was not motivated merely out of an observation that swallowing the pill would prove challenging and that the medication was not necessary at this stage of life (technical competence). Rather, she was also concerned for preventing the patient’s “last memories to be struggling to swallow this” (p. 137). Thus, this nurse made a decision about a particular pill for a particular patient in a particular circumstance, through broader consideration of the impact that this moment would have on the patient’s lived experience of dying. This resounds with my descriptions of the simple acts of caregiving that are part of the standard of care here as having moral significance. A particularly illustrative example was the senior nurse advising the more junior nurse to only perform mouth care for a particular patient, previously delirious, now unresponsive, with water from the cooler, as she knew that this patient had despised the taste of tap water when she was awake.

According to Austin (2011), “To state that one is a nurse is to make not only a professional claim but a moral one” (p. 161). Here Austin is speaking to the fundamental ethical commitment that nurses make towards society to enter into caring relationships that are characterized by genuine and compassionate engagement. This relational ethic is both possible and necessary because of the *closeness* of nurses to the lived experiences of their patients and families. Austin writes that “nurses are up-close and personal to the human condition, to death and dying, to suffering and survival, to

life's tragedies and joys" (p. 161). A common conception within larger society is that such proximity to human suffering places the nurse at increased risk of burnout or emotional exhaustion. Indeed, I reported in the findings of this study that caregivers in this hospice are accustomed to receiving questions from their own personal acquaintances about "how depressing" it must be to work with dying people on a regular basis. Beverly Hall (2005) asks "how do nurses become wise instead of distressed when enclosed into a circle of suffering human kind, a world of untold injury that they cannot fix?" (p. 71). She then answers her own question by suggesting that "Wisdom surfaces when involvement overrides the reaction to create distance from patients in order to avoid pain" (p. 71). There appears to be evidence to support this claim. A recent systematic review of burnout in palliative care, for example, identified that spending time and establishing effective communication with patients and families in palliative care environments are protective against the development of burnout amongst professional caregivers (Martins Pereira, Fonseca, & Carvalho, 2011). The findings of this review suggested that caregivers themselves benefit from involvement rather than from creating distance. Such involvement leads to a feeling that they are making a significant positive difference in the lives of others; "These professionals therefore develop a sense of personal gratification, which leads to greater personal and professional satisfaction" (p. 323).

Nurses in this study got up-close to their delirious patients. Rather than retreating from what is potentially a disengaging situation, nurses strived for connection across the delirium void. This took great courage and strength of nursing character. They pushed through their initial frustration that in delirium "you can't do anything!" to offer consistent and reassuring presence. Nurses offered "tender loving care" to patients' perceived to be mentally suffering and further offered families ways to be with them in loving presence.

Recently published clinical practice guidelines on the palliative care of older adults with delirium at the end of life remind us that "A person with delirium at the end of his or her life is no different from a person who does not have delirium from a spiritual perspective. They can have fears and existential distress that need attention" (Brajtman et al., 2011, p. 45). Through basic care of the delirious patient, hospice

caregivers ensured that they were providing the care and attention that their patients needed and deserved. Signs of delirium potentially signaled an unmet care need, and in addition to mobilizing traditional delirium symptom management (e.g., antipsychotic medication, reassurance, reorientation, provision of a quiet atmosphere), such signs of apparent distress also mobilized a comprehensive assessment as to the patient's *overall* wellbeing. E.g., Is the patient in pain? Do they need to be cleaned? Do they need to hear from someone in particular, and if so, can we get that person on the phone?

This “up close” approach by hospice caregivers in response to their delirious patients is important to highlight, as there is evidence that it may not be typical in other care settings in which delirious patients find themselves. Poole and Mott (2003), for example, conducted a focus group study with nurses working in a large teaching hospital about their work with agitated older patients, including agitation as a result of delirium. They found that nurses’ often felt feelings of frustration and irritation toward such patients. Nurses felt that agitated patients took too much of their time, e.g., “nothing else gets done” (p. 309) and that this time pressure seriously affected the way they organized care of their agitated patients: “Sometimes it [mechanical restraint] makes them more agitated but you’d rather that so you can get out and get some of the other work done and come back to them later and calm them down” (p. 309). Comments by these nurse participants such as “here we go again,” “you can have her,” and “why do I have to look after him?” (p. 309-310) demonstrated that agitated delirium can irrevocably threaten the relational engagement between nurse and patient. Similarly, a participant observation and critical discourse analysis study of nurses’ linguistic framings of delirious patients in hospital (Schofield, Tolson, & Fleming, 2012) shows how nurses describe their acutely confused older patients as disruptive, destructive, aggressive, threatening, and uncontrollable. During acute confusion, such discursive constructions take precedence over discourses of dignity and compassion, where the idea of “patients as persons who were undergoing a potentially frightening experience rarely featured in the nurses’ constructions” (p. 172). My interpretation here is that there appears to be a crucial distinction between nurses who primarily conceive of the challenges associated with delirium as problems for themselves and their work, and nurses who primarily recognize and respond to

delirium as a problem for the patient and family's experience. A telling example of the implication of such distinction in my study was when the daughter of a patient explained the difference in nursing approach that she noticed between being in hospital and being here in the hospice. In hospital, if her mother was agitated but she was present to supervise, the nurses made her feel that they were "OK with that." In contrast, here in hospice her presence and availability to supervise her mother did not affect the nurses' recognition that delirium was interfering with comfort, and therefore demanded attention and response. Thus, while hospice caregivers in my study did speak to the fact that delirium can "complicate matters," e.g., patients' pulling out catheters and syringe drivers, climbing out of bed and falling down, caregivers' analyses remained focused on the potential distress this caused the patient and family and the resultant implications of delirium-as-suffering for a good death. In this way, hospice caregiving practice was consistent with exemplary practice as described by Perry (1998):

...their patients were their reasons for being nurses. As these nurses considered each nursing action or interaction they thought about how it would affect the quality of life for that particular patient. (p. 137)

To return to the idea of palliative nursing enacted through attention to basic care, I found that the ways in which hospice caregivers ascertained the implication of delirious manifestations to the patient's quality of life was through continuous reflection of a "basic" question: How is this patient doing right now? Answering this question required them to *know* their patient: their likes and dislikes, their personality, and their typical patterns. While lengths of stay in the hospice were often short, such knowing was nevertheless enabled through continuous team discussions about changes observed and in-depth conversations with family members who were most familiar with the patient's biographical and historical context. Asking and answering this basic question for their delirious and potentially suffering patients was therefore a form of "engaged moral reasoning" (Tanner, 2006, p. 209). According to Tanner's model of clinical judgment in nursing, such reasoning is a feature of expert nursing practice, whereby nurses "enter the care of particular patients with a fundamental sense of what is good and right and a vision for what makes exquisite care" (p. 209).

Expert clinical reasoning in nursing arises from genuine engagement, “always in relation to a particular patient and situation and informed by generalized knowledge and rational processes, but never as an objective, detached exercise with the patient’s concerns as a sidebar” (p. 210).

The Road to the Good Death

In several places in the findings chapters of this thesis I referred to the “road to the good death.” In this section, I will explicate the meaning of this metaphor. My discussion draws largely from a study by Johnson et al. (2000) that examined dialogue between team members and families regarding the withdrawal and withholding of life supportive interventions in a large urban university hospital intensive care unit. While this is obviously a very different care environment than the hospice that I studied, the relevant commonality is that in both contexts, it is within the caregiver-family relationship that negotiations of care decisions take place. This is because in the intensive care environment, very much like in this hospice, patients are often unable to participate in such negotiations because they are unconscious, cognitively impaired, and/or pharmacologically sedated.

Johnson et al. (2000) interpreted discussions between caregivers and families in their study as contributing to a therapeutic narrative, meaning “a story which frames therapeutic events as well as the patient’s illness experience in a meaningful and psychologically comforting way for families and health care providers alike” (p. 275-276). This framework of analysis appears consistent with a relational ethical approach to understanding nursing practice, whereby interactions between nurses, patients, and families are understood as an exercise of co-authoring an overarching story that is habitable, i.e., that we can all live with (Abma, 2005; Meiers & Brauer, 2008; Gadow, 1996). Johnson et al. suggest the motivation for striving toward such an overarching story lies in “its promise to bring desperately desired coherence, meaning, and a confident basis for action” (p. 277). I certainly found a search for coherence and meaning to be a feature of caregiver-family relationships within the hospice. Families often lacked any prior experiences with death and dying, or did have previous experiences that were traumatic and therefore that affected their expectations for the current situation. Hospice caregivers supported these families by providing consistent

messages about what normal dying looks like as well as by reframing potentially negative interpretations into more positive ones, e.g., *Your loved one can't talk back to you any more, but look how peaceful and comfortable he looks*. Further, the need for a shared story that provides a “confident basis for action” resounds strongly with the findings of my study. When family members held similar interpretations as hospice caregivers as to the patient’s current situation and the implications of that situation for reaching a good death, caregivers were more easily able to implement interventions that they deemed helpful and necessary in providing for the patient’s overall comfort. Examples included giving medications for apparent distress (e.g., pain, restlessness), or inserting a foley catheter so that a weak, unstable, or confused patient would not need to get out of bed.

In exploring the co-authoring of therapeutic narratives in their study, Johnson et al. (2000) found that their participants shared a common focus on “how it will all turn out” (p. 279). These authors invoke the metaphor of *path* to describe the patient’s clinical trajectory as experienced by caregivers and families. This metaphor implies “directionality,” where paths can alternatively be described as “rocky,” or “smooth,” and are “ultimately about destinations or endings” (p. 279). These metaphors are helpful in considering the relationships between hospice caregivers, patients and families in the context of hospice care and their collaborative orchestrations of good deaths. In this setting, hospice caregivers frequently invoked the metaphor of *journey* in describing the patient and family experience of dying toward death. This metaphor implies a dual focus on process and destination. The process orientation of the good death in this setting means that the patient’s symptoms are optimally controlled, and that they (patient and family) are given the space needed to accomplish whatever they desire and to make the most out of the remaining time they have left. The destination focus of the good death, meanwhile, means that the moment of death will be quiet, peaceful, and dignified. This is most commonly accomplished when the patient is asleep, in bed, and not exhibiting any signs that are disturbing to others because of an inferred sense of discomfort or distress (e.g., bleeding, shortness of breath, agitated or fearful awareness). The destination focus also means that when all is said and done, the patient will be remembered by family to have received good palliative care and to have

experienced a good death. Thus, a focus on process itself contributes to the creation of a satisfactory ending (destination) to the therapeutic narrative.

Hospice caregivers' own descriptions of the meaning of a good death involved descriptions of their role in providing for patients and families a "smooth" transition, whereby they "have a handle" on the situation and in which there are no "surprises" that thwart their efforts. This demonstrates that the creation of good deaths in hospice care is not necessarily straightforward, but rather involves careful negotiation of potential roadblocks along the good death journey. It is my overall impression, based on my experience of fieldwork here, that the relative ease (smoothness) of traveling along this metaphorical road toward the good death is determined by the extent to which hospice caregivers and patients' families are *on the same page*. Being on the same page (an expression derived from hospice caregivers' own language) means a shared understanding and agreement about what is happening and what needs to happen to enable an optimal end-of-life experience. For example, a shared understanding about *what is happening* might mean an acknowledgement by family that the patient is imminently dying and that he or she is currently uncomfortable. In such a situation then, a shared understanding about *what needs to happen* might mean agreement about certain medications that will be administered as well as agreed upon ideas around the best ways of interacting with the patient at this stage, e.g., decreasing the level of stimulation in the room. When all concerned share the same overall interpretation of the patient's comfort level and agree that care strategies and clinical management are appropriate, this fosters harmony within the hospice caregiver - family relationship.

Bringing families on board is the process by which I suggested that hospice caregivers invite and encourage families to come onto this *same page*, to thus enable a smooth journey toward the good death. Again, the analysis of Johnson et al. (2000) is helpful in understanding attempts to bring families on board as active and deliberate action by hospice caregivers. In the intensive care unit context that was the setting for their study, the overarching cultural orientation is to save life. Therefore, patients and caregivers alike hoped for recovery and to overcome death. In many situations, however, the certainty of death eventually became clear to caregivers. The authors

write that:

Once there is narrative commitment to the inevitability of a particular patient's death, end-of-life narratives begin to work to dispel hope. Many families, we learned, feel the need to hear that there is "no hope" before considering to withdraw or withhold life support. (p. 279)

Thus, when the circumstances of an individual therapeutic narrative change to imply a certain outcome, caregivers and families work to co-author a story that, in spite of this outcome, will nevertheless be meaningful and comforting.

At the same time as the narratives work to dispel hope and convey the inevitability of the patient's death, they also begin to hold out the possibility of an unavoidably sad yet satisfactory ending to the patient's story. Having formulated less desirable endings in which there is prolonged suffering and loss of dignity, limitation of treatment or life support is proffered as a means to a "good" and timely death. (p. 282)

In my study, what can analogously be termed a *narrative commitment* occurred when patients with terminal delirium were deemed by hospice caregivers as having no more opportunity for "quality awake time." In these situations, the hospice caregivers judged it to be morally preferable for the patient to spend the remaining interval between now and eventual death asleep. At this stage of the dying trajectory, patient wakefulness was not seen to contribute anything of value to established understandings of a good death. Rather, it meant that the patient was being left in a tormented state that would create for families images that are disturbing to witness and harmful for their bereavement. Ways in which professional caregivers in Johnson et al.'s (2000) study helped families to navigate the narrative commitment of "no hope" included indirectly transmitting this message by reciting the "litany of medical problems experienced by the patient" (p. 280). Likewise in my study, hospice caregiving practice around supporting families' acceptance that to be awake in terminal delirium was to be suffering also happened indirectly. Hospice caregivers would not coldly tell families, as a simple matter of fact, that the patient now needs to sleep. Rather, they would solicit the family members' perceptions on what they themselves were witnessing, e.g., *When he is awake, what do you see? Does he look comfortable?* They would simultaneously proffer their own perceptions of what they

saw and consistently reinforced, collectively as a team and across shifts, that they observed the patient to be uncomfortable. Most significantly, they made it known that they could provide for a better alternative. Thus, bringing families on board in this context was a process of gradual negotiation. Previous research with families of terminally delirious patients has shown that there is a high degree of ambivalence about treatment strategies that will result in loss of the patient's wakefulness, especially when families interpret these treatments as removing their opportunity for meaningful interaction with their dying loved one (Brajtman, 2003). Hospice caregivers in this setting were cognizant and respectful of this. They described their role as providing for a "balance" between assisting families to be present for their loved ones in meaningful ways whilst still attending to the patient's suffering. To this end, they explicitly offered to families *new ways* of being with and interacting with their dying loved one. For example, they would coach families on how to be with the patient in silence, or on ways to gently hold the patient's hand without stimulating them to the point of agitation. In this way hospice caregivers facilitated both a process of letting go while holding on (Bruce et al., 2011).

Hadders (2011) conducted a research study in a Norwegian hospital palliative care unit that examined the ways in which nurses prepare family members for the death of the patient and include them in after death care. His findings are relevant here for understanding the ways hospice nurses engaged with families toward helping them structure a moral experience of hospice that would be comforting to them over time. According to Hadders:

Biomedical signs of imminent death play an important role when it comes to including relatives in good time and making them aware of the fact that biomedical death is approaching. Information about medical signs of imminent biological death constitutes a powerful tool for nurses as they negotiate relatives' participation in leave-taking events. Unfamiliar biomedical phenomena are explained and put in a timeframe. (p. 227)

This is consistent with the care practices that I observed in hospice. Changes in consciousness and cognition associated with terminal delirium were often explained to families, through repeated verbal exchanges and through provision of written information, that these signs herald impending death. As hospice caregivers prepared

families for death through reflection of the changes observed in the patient, they consistently offered to families diverse ways of *being there*. They assessed that some families needed to be given permission around how to interact with the patient, e.g., *Can I touch her? Can I talk to him?* Other families needed permission to be present or to be absent, e.g., *Can I leave for the night?* In these situations, “permission” was about validating for families the ways of being toward the dying patient and dying experience that they themselves seemed to identify as most helpful to them. So, a family member who would ask whether she should talk to her previously delirious and now unconscious father might be told that yes, she should do that, because he can still hear her. Meanwhile, a family member who appeared exhausted and upset by her mother’s delirious behaviour might express a desire to leave and would have this choice affirmed by hospice caregivers.

Relationships with Family

The previous discussion has explored the centrality of relationships that hospice caregivers develop with family members as highly influential for how smooth or bumpy the road to the good death is in this setting. In this section, I further explore ideas of the hospice caregiver - family relationship.

One area in which numerous tensions became apparent was in considering the ways that families were part of the collaborative construction of good deaths, but also sometimes seemed to *distract* hospice caregivers in their enactment of good death practice. First, some hospice caregivers explicitly tied family perceptions of the dying and death experience to its evaluation as good or bad, i.e., the good death is when the family gets what they want out of the experience. In this way then, the ethos of providing for good deaths in hospice caregiving is about helping families to achieve their own goals, consistent with a practice philosophy of family-centered care (Gottlieb & Feeley, 2005). Hospice caregivers take the pulse of the family, determine their goals, wishes, and expectations, in light of prior experiences as well as current strengths, resources, and challenges, and against this context provide for them whatever support will help them to live their loss in the most health promoting way possible. The findings show that families are welcomed into the hospice and are provided with resources to enable them to benefit optimally from palliative care. They also show, however, as

described above, that a smooth road to the good death requires that families and hospice caregivers need to be *on the same page*. One meaning of being on the same page was that family knew and respected the limits of their own space within the hospice. Families who entered the nursing station or the medication room uninvited, for example, risked being considered disruptive by the hospice caregivers. Being on the same page also meant not interfering with hospice caregivers in their attempts to provide palliative care to the patient (e.g., giving medications). When family members appeared to interfere with the hospice caregivers' ability to deliver what they saw as optimal and necessary patient care, this created tension that transformed the relationship from supportive to adversarial. This has been observed in other research of family nursing practice. Stayt (2007) for example found nurses in intensive care to be motivated to work with family members in supporting their needs and interests, but only to the point where such work did not detract from their ability to effectively take care of their patients. As the following excerpt from that study shows, nurses feel torn when they perceive the needs of the patient and the needs of the family to be in direct opposition:

I was trying hard to keep on top of it all [responding to a critical clinical situation] but the family kept getting in the way. They just kept coming in from behind the curtains when I had told them to wait in the relatives' room. I know it sounds mercenary because obviously they were really worried and needed support but, the patient's wellbeing has to come first and that is final and on this occasion I had to be very firm with the family as I felt... I just felt that they were preventing me from doing my job. (p. 627)

Stajduhar et al. (2008) conducted a study that sought to understand how family caregivers of dying cancer patients view their roles in relation to the palliative care system. The methodology for this study was a secondary analysis of qualitative data from thirty-six bereaved family caregivers, collected in the context of a larger mixed-methods research project about family caregiver coping in end-of-life cancer care. The authors found that this sample of bereaved family caregivers conceptualized two roles for themselves within the palliative care system: client and co-worker. These roles were not mutually exclusive and could be occupied simultaneously. Situating oneself as a client meant expecting a certain degree of attention and support from palliative

caregivers as part of the unit of care. Thus, family members articulated that they themselves had legitimate needs for support and hoped the palliative system would provide them with such support. Situating oneself as co-worker, meanwhile, meant that family members sought recognition from their palliative caregivers for the great deal of caregiving work that they provided to the patient. They felt that they often had expert knowledge about the patient's care, by virtue of their experience in caregiving, and they thus desired to play an active role in the caregiving process. They sometimes felt the need to advocate for what they thought was best for the patient. According to the researchers' analysis of this data, family caregivers not only situated themselves in these two roles, but also *were situated* into them by the palliative care system. In both cases, families sometimes resisted being positioned in these ways. Being situated as a co-worker, for example, sometimes meant being expected to provide care that the family did not feel prepared for. This form of positioning was not observed in my study, though the example above of the delirious patient's daughter who said she was expected in hospital to monitor her mother's safety would be an example of this. In this hospice, while a certain degree of participation in the patient's care was welcomed when desired by the family, it was never required or expected. Being positioned as client, however, seems a relevant frame through which to interpret the hospice caregiver - family relationship in this setting. As described in the findings chapters, families are strongly encouraged to "sit back" and to "be a family member again," leaving the *tasks* of caregiving to the hospice staff and volunteers. Families who interfered with the provision of optimal palliative care to the patient (e.g., not allowing a nurse to administer medication), or who did not recognize the limits of their own space within the hospice (as described above) can be understood as resisting their positioning as client and advocating for their role as co-worker. Stajduhar et al. suggest that the implication of their results for family-centered models of palliative care is to recognize that "family caregivers do not believe themselves to be *only* care recipients" (p. 1796, original emphasis). In this ethnography, when families were *on board* with adopting the role of client and readily allowed hospice caregivers the freedom to provide palliative care for the patient in the ways that caregivers felt appropriate, this seemed to facilitate an ability for families to experience the hospice as a safe place.

Conversely, when family members positioned themselves as co-workers and resisted hospice caregiver explanations and interventions, tense relationships would sometimes develop. These families seemed less likely to experience the hospice as a safe place. Recall, for example, the family who described their loved one's delirium as resulting from receiving a dose of morphine that he did not need (according to them), "and then we lost him." Even though at the time of my interaction with this family the patient appeared comfortable, and they indeed expressed relief at this, they nevertheless seemed to maintain an overall attitude of mistrust toward hospice caregiving practice.

It was very interesting for me to realize, when considering notions of people being on the same page and bringing people on board to enable the good death, that these ideas seem less important for patient-caregiver relationships than for family-caregiver relationships. To be clear, hospice caregivers do engage in much of the same work with patients around getting them on board with the hospice way of life. Such practices include helping patients to prepare for death, encouraging them to accept comfort care (e.g., medication), and helping them to acknowledge functional loss (e.g., the need to stay in bed when too weak to mobilize even with assistance). However, while patients coming on board is certainly helpful toward smoothing the road to a good death, it does not seem to be an absolute requirement. That is, good deaths can happen even if the patient never comes on board with the perspectives or approaches of hospice caregivers. I suspect this is because when all is said and done, while a patient who never came on board will be remembered as a challenging case, he or she will nevertheless be remembered and respected for dying his or her own way. The clearest illustration of this would be a patient who categorically refuses analgesia and experiences terrible pain as a result.⁹ This would likely cause hospice caregivers a certain amount of distress, frustration and confusion as to what their role should be in this situation, i.e., *what are we here for if not to alleviate his pain?* Respect for the patient's right to self-determination, however, would take precedence and would be woven into an understanding that this patient's death was a good one because the

⁹ I did not observe such a case during fieldwork, but was told by hospice caregivers that such cases, while rare, do happen.

patient died on his or her own terms. Conversely, the ethics of hospice caregiving practice do not afford families the right to make these types of decisions *for* the patient. To continue with this pain example, to not medicate a patient who was writhing in pain and unable to communicate his or her own wishes because of a family member's reluctance to accept pain medication would not occur. In such a situation, the most likely scenario would be a "family meeting" in which hospice caregivers would delineate their role and commitment to providing for the patient's comfort, toward the desired outcome of being permitted to administer analgesia. Therefore, while processes of bringing families on board in hospice caregiving are directed at promoting families' own wellbeing, where it is believed that when they are on board they will more fully benefit from their time in hospice and experience a more positive bereavement, these processes are also directed at enabling the hospice caregivers to fulfill their primary ethical responsibility: the optimal palliative care of their dying patient.

The relationships that hospice caregivers develop with families have direct relevance to delirium care. Manifestations of delirium often develop insidiously, and because families know the patient the best, they are an important asset to hospice caregivers in their assessments of conscious and cognitive change. Families are often the first to notice that something that the patient says or does is "inappropriate" in the context of their personality or typical behaviour, an important dimension of mental state assessment as described by the findings of this study. Trust between hospice caregivers and a family facilitates open communication between all who interact with the patient about what is happening and what is being observed. Conversely, when families are not on board with the care being offered by hospice caregivers, collaborative engagement toward knowing and responding to the patient's mental state is more difficult.

Mind-Body Dualism

One of the tensions that posed a particular analytic challenge in this study was the way in which hospice caregivers seemed strongly committed to a practice ethic of whole person care, and yet repeatedly alluded to a mind-body split when speaking about their patients. My findings in this regard are remarkably consistent with those of

Copp (1997), who interviewed hospice nurses caring for terminally ill patients in the United Kingdom. Copp found that as patient death approached, these nurses increasingly drew conceptual divisions between the bodies of their patients and their patients' personal selves. Like me, this caused Copp some concern, where she noted that such a conceptual separation "clearly departs from the notion of viewing the body and self as an integrated being, which has been adopted by nursing in general, and by hospice nursing in particular" (p. 8). For the nurses' in Copp's study, the function of distinguishing between the patient's body and self was an effort to gauge the patient's readiness to die. Similar to the nurses in my study, the notion of synchrony was important for such an assessment. For example, one nurse in Copp's study had the following to say about a particular patient:

I think her body was physically very, very weak, but I think, mentally, spiritually she wasn't ready to let go. The only way I could describe the weeks leading up to it was like a wounded animal who was just desperately trying to get up all the time and just couldn't rest and couldn't be at peace. She was just fighting, fighting, but I think that morning we actually reached a point where she actually made it very clear she'd had enough. She was ready to let go...she realized she was dying. She just wanted to be out of it, she wanted to be less aware. So I think we reached a point where mentally and spiritually she was ready to let go but, unfortunately, the family were not at the same point. (p. 8)

In this example we read asynchrony at three different levels, body, self, and family. First, the body appears ready for death but the patient as a person is fighting this. Her resistance to her own bodily deterioration stems from a mental and spiritual resistance to her own demise and manifests as a restlessness, trying to "get up all the time," and precludes any sense of "peace," i.e., a good death. Then, according to this nurse, when the patient does eventually reach a place of synchrony within herself, when she evidences in body and in spirit a readiness to die, her family, "unfortunately," does not. Thus, in this analysis, a prerequisite for a seamless and presumably better death involves a readiness that is uniformly experienced across the patient's physical (body), personal (mental/spiritual), and social (family) dimensions of self.

For Copp (1997), the separation of patients' physical and personal selves by hospice nurses was a way of understanding and describing patients' readiness for death. This was also the case for the hospice caregivers I describe in the current study,

and I would add that their conceptual divisions of their patients' personal and bodily selves informed not only an assessment of readiness to die, but also a moral assessment of whether the patient *ought* to die. When patients' bodily and mental deterioration came uncoupled, resulting for example in a seemingly lifeless body that "lingered" for days or weeks, hospice caregivers would express that it was now time for the patient to die, and would explicitly wish for this. Interestingly then, it appears that in this hospice one of the motivations for such a mind-body division might be a deliberate effort to safeguard a felt sense of the patient's personhood. That is, when the patient deteriorates to a point where bodily or mental changes have effectively made the patient unrecognizable, caregivers may be attempting to conserve a dignified image of the patient by distancing the body in the bed from the person they have come to know. Copp posited a similar explanation, whereby she wondered if the nurses in her study were separating their understandings of their patients' dying bodies from their understanding of their patients as people, where the only alternative "would constitute the total annihilation of the person; body and self" (p. 10).

Concern over conceptual divisions such as these in the nursing literature is generally motivated by fear that such conceptualizations fail to apprehend the ontology of the person as a unified, whole being. Thorne (2001) has called this the "holistic imperative" of nursing's theoretical discourse, which arises out of a perceived need to protect an "intact and vital understanding of the person" against the "serious potential for fragmentation and dehumanization" (p. 260) within the mainstream biomedical healthcare context. Copp (1997) however did not find such fragmentation or dehumanization to result from nurses' conceptual split of patients' bodies and selves. Rather, these conceptual separations "provided a mechanism for unravelling and understanding the emotional and physical complexities of the phenomenon of dying" (p. 9). For these nurses, the mind-body split was not an ontological fallacy, it was a heuristic. It was their way of constructing a "practice-oriented conceptual map" (p. 9) or "everyday working framework" (p. 10) to make sense of the dying patient's situation. This resonates strongly with my interpretations of hospice caregiving practice, where I came to understand that hospice caregivers' repeated divisions between "physical" and "emotional" dimensions of human experience were not

interpretations of the patient as a fragmented being, but had more to do with figuring out how to prioritize and situate themselves in response to whatever was most at stake in each individual patient situation. This approach is consistent with the guiding philosophy of palliative care nursing, which encourages a conceptual division of the patient's experience along physical, psychological, social, and spiritual dimensions toward the specific goal of engaging with the patient as a whole (Ferris et al., 2002).

According to Thorne et al (2004), considerable attention in nursing writing has been paid to dichotomizing conceptualizations of nursing as either purely holistic or purely reductionist. These authors plainly suggest this is a mistake that limits our potential for a meaningful and insightful scholarship that might encourage us to look beyond the restrictive confines of such binary logic. In a phenomenological study with nurses working in a hospice in the North West of England, Evans and Hallett (2007) provide excerpts from research interviews where nursing language is rife with references that are at once holistic and reductionist. These nurses were concerned with promoting a sense of comfort for their patients, where comfort was described as a "holistic phenomenon" and a "total experience" (p. 747). Comfort was described as an overall sense of wellbeing in body, mind, and spirit. Interestingly though were the nurses' uses of conceptual demarcations between body, mind, and spirit to grasp and describe the meaning of *total* and *holistic* in this context. Thus, comfort was to experience "a sense of ease with their physical bodies," or "a sense of ease in a psychological as well as a physical sense" (p. 747). Nurses described patients for whom they cared with "no physical pain but an awful lot is going on in their mind" (p. 747), and stated that "dying is not *just* a problem of physiology" (p. 747, emphasis added). Further, while hospice nurses in their study were familiar with and motivated to work from a framework of holism, they nevertheless prioritized bodily comfort over other broader realms of wellbeing in dying. "Freedom from pain" was thus "a major component of the nurses' goal of comfort" and, according to one participant quoted, "often our *first* goal" (p. 746, emphasis added). This is consistent with the findings of my study, where assessment and relief of physical pain was "primary" for hospice caregiving practice. Also consistent with the findings of my study, Evans and Hallett found that while hospice nurses managed physical pain toward providing the patient

an opportunity for broader experiences of comfort in dying, there was recognition that alleviation of physical pain might paradoxically “increase patients’ awareness of other insidious emotional issues, which threaten their sense of rest and peace” (p. 747).

Hospice caregivers in my study emphasized the inseparability of the physical and mental dimensions of their patients and yet persisted in their conceptual separation of these, at times, for specific purposes. This separation was not to the detriment of acknowledging their patients as a ‘whole’ persons, but rather was itself a mechanism of engaging with what was most significant within the multidimensionality of patient and family experience. It was also a means of interpreting how various issues may relate to each other and how, as a team comprised of individuals with different abilities and expertise, they might optimally situate themselves in response. According to Thorne (2001), acknowledgement of the multiple “parts” that constitute the person who is the recipient of nursing care is necessary for a genuinely holistic practice. She suggests that good nursing care involves the ability to preferentially employ different gazes toward specific parts with an eventual view of better understanding the whole. In this way, the nurse comes to understand what is most significant for this person’s health and wellbeing at this time and in this place. Flaming (2001b) continued Thorne’s argument and wrote that in clinical reasoning “Reductionism and holism should have a symbiotic, nonhostile relationship. They are partners, not adversaries. By definition, wholes need parts, and parts need wholes” (p. 263). Reductionism was employed by hospice caregivers in this study when they directed the focus of their attention and clinical reasoning toward one dimension of the patient’s experience, e.g., mental state, or when they enacted specific strategies to respond to a patient’s discomfort, e.g., giving an antipsychotic medication in response to delirious agitation. Such reductionist practice however was not pernicious to understanding and engaging with holistic care, but rather enabled this. Focused attention on one dimension of patient wellbeing, e.g., mental state, subsequently allowed for the insights developed around this specific dimension to be contextualized and reexamined, often through team discussion, against broader dimensions of what was *known* about this particular patient. Swift and decisive implementation of a pharmacological intervention for observed mental suffering, e.g., delirious agitation, allowed the nurse, once the patient was “settled” (a

term used consistently by hospice caregivers), to consider other implications of the patient's mental unrest for his or her good death. It also enabled the nurse to engage in other work that related to broader dimensions of wellbeing in dying. This might include working with the family to discover hypotheses underlying the restless agitation and/or to provide them with information that would support their ability to be present with the patient.

The ways in which hospice caregivers conceive of their dying patients' physical bodies and mental selves, i.e., at once unified and separate, provides an important context within which to analyze the diverse ways in which manifestations of delirium were found to influence caregivers' explanations to families regarding the *personhood* of the delirious patient. In their conceptions of what delirium means for the identity of their terminally ill patients, hospice caregivers appeared to engage competing and contradictory interpretive frameworks. On the one hand, there was popular appeal to the idea that irreversible and distressing delirium signified social death. This understanding proved useful, for example, when attempting to soften for families the pain caused by delirious behaviour that was perceived as hurtful. Hospice caregivers readily encouraged families to come on board with the idea that "*that's the disease talking, that's not your father.*" Interestingly however, such appeals did not detract hospice caregivers from their commitment to a person-centered approach to care that involved engagement with the patient's social biography and affirmation of their lived life and retained personhood through to (and beyond) their death and departure from the hospice. Thus they made every attempt to recognize the inherent personhood of their delirious patients by striving to connect with them, maintain their dignity, and provide care in ways consistent with what they knew of their likes, dislikes, and personality (e.g., softly playing music that the patient had previously enjoyed). Further, even though hospice caregivers might encourage families to embrace an idea of *this is not my father talking*, they also knew that caring for the patient as the person he or she is was important to family members witnessing that care. Therefore, they were very careful to demonstrate this acknowledgement of personhood to families, demonstrating that *this nurse is not just caring for a patient, she's caring for my Dad.*

To return to the study by Hadders (2011) of the ways in which palliative care

nurses prepare family members for the death of the patient and include them in postmortem care, “Protecting personal integrity is seen by [palliative unit] nurses as a general aspect of their care of patients, whether conscious, sleeping, sedated, or dead” (p. 229) Nurses in his study offered to families diverse ways of being present after patient death; would they like to wash the body alone or with the nurse, would they prefer to be present while the nurse performs the care alone, or would they prefer not to be present at all? When families chose to participate in after death care with the nurse, Hadders found that “Throughout postmortem care, [palliative unit] nurses and relatives oscillate between attitudes of nearness to and distance from the deceased, who can be experienced as both a sentient being and an inanimate body” (p. 231). For Hadders, through post-mortem care nurses engage in “parallel processes [that] accentuate both social life and social death” (p. 231). In this way, again, palliative nurses are seen to facilitate for families a process of letting go while holding on (Bruce et al., 2011). The implication then for the diverse ways in which delirious patients in this study are conceptualized is not about which interpretation prevails (i.e., the patient as person or the patient as dying body) as both interpretations can be meaningful, serve a useful purpose, and be simultaneously held by caregivers and families. While such competing interpretive frameworks were surprising to discover during fieldwork, it is reasonable that in the context of a condition which by definition follows a fluctuating course, caregivers and families require a flexible and creative approach to working through the variety of delirious manifestations that they witness. This is particularly important considering that the ways in which delirious patients interact with and relate to the world around them often changes from one moment to the next.

A Final Reflection on Relational Ethics

In this section, I briefly reflect on the performance of relational ethics as a theoretical lens for this study. Relational ethics calls for the recognition that *every* encounter between caregivers, patients, and families is an ethical moment (Bergum, 2013). Ethnographic fieldwork inspired by a relational ethics perspective thus required not only the observation and documentation of relational encounters but also a continuous questioning about the moral meaning of such encounters. By highlighting

“the moral flavor that is intrinsic to the daily activities of [caregiving] practice” (Wright et al., 2009, p. 225), deeper and more authentic interpretations about hospice care were enabled. For example, practices such as offering explanations about what normal dying looks like to families, which includes the idea that cognitive change along this trajectory is anticipated and acceptable, was found to be much more than provision of information. Rather, it is a process of *structuring family moral experience*. Further, the relational ethical emphasis on inter-subjectivity enabled a strong understanding of the moral meaning of *knowing* in the caregiving encounter. The value of knowing patients and families as unique individuals was not only out of concern for dignity and personhood (though this was important) but also to enable an interpretation of the patient’s *mental state* and to position oneself in an optimally supportive way. Thus, relational nursing care is better nursing care. At the same time, findings from this study add nuance to the idea that honouring the patient as a subject, i.e., an embodied and lived life, is always a necessary ethical commitment of the nurse (Bergum, 2013). While this idea enabled me to see and understand how hospice caregivers carefully attend to the lived body of their delirious and dying patients and to appreciate the moral significance of this practice, hospice caregivers simultaneously discounted the lived body of their delirious patients when they promoted an idea of social death for the sake of family wellbeing. This action was purposeful and was itself motivated by a relational ethical commitment. The goal was to preserve the integrity of the patient-family relationship as lived by the family member, and to protect them from being harmed by images and behaviours that rendered the patient unrecognizable and the space around him or her uninhabitable.

Ultimately, a relational ethical analysis of caregiving practice focuses on the nature of engagement between caregivers and patients/families in the care setting. According to Bergum and Dossetor (2005), relational engagement “is found in the shared moment in which people have found a way to look at something together” (p. 103). In this study, I have presented an analysis of how the people belonging to one EOLC community (nurses, other caregivers, patients and families) all find a way to look at something together. Through their connectedness and mutual interdependence, they create collaborative interpretations about the meanings of a good death, of dying with

delirium, and about the ways in which these two notions interconnect.

Limitations

In offering this thesis to the wider clinical and scholarly communities in nursing and related disciplines, I need to explicitly account for research limitations. Research limitations are not weaknesses. Rather, they are features arising from the epistemological and methodological commitments of this research that affect the extent to which the interpretations offered here can be read and transferred to other contexts.

As described in Chapter 3, the writing of this ethnography was largely a personal journey. This means that my own subjectivity cannot be separated from what I am presenting. A continuous stream of individual and moment-to-moment decisions during fieldwork about whom to observe, when to speak, and what to write have culminated in the final product that is this thesis. My own identity as a palliative care nurse, my beliefs and values about nursing and about the good death framework, and my novice status as a first-time ethnographer all shaped my conduct in the field and the scope of my analytic horizons. All other things being equal, I do not believe that another researcher would yield an identical product as the one offered here. This is reasonable and satisfactory, I believe, because ultimately the worth of this work will be decided based on the relevance, meaningfulness, and credibility of the interpretations offered. The research question guiding this study does not imply one single, unifying, correct answer. Rather, it provides a space for multiple perspectives and dialogues, within which this thesis makes its contribution.

Several approaches were adopted in this study to counterbalance my own subjectivity throughout the research process. First, my research supervisor and thesis committee were very involved in all stages of this project. From early stages of study design, throughout fieldwork, and right through to the end of the writing stage, regular contact with this research team ensured that I remained connected to the world outside of the hospice context. This meant being continuously challenged to account for what I was seeing, how I was seeing it, and what it might mean. By constructing my interpretations in constant conversation with mentors who had not been to the hospice, I was assisted in expanding my thinking beyond the local confines of this

setting and toward questions of meaning and relevance for the broader contexts of nursing and palliative care. Further, while my primary supervisor is both a palliative care nurse and a qualitative researcher with expertise in delirium, one committee member is not a nurse (she is a medical anthropologist with expertise in ethnography and palliative care) and another's primary area is not palliative care (she is a nurse and has expertise in qualitative research). This mix of experience and skill within the project team resulted in different but complementary angles of vision through which to view and interpret the hospice, providing for a multiplicity of perspectives as well as checks and balances along the way (Russell & Gregory, 2003).

I described in Chapter 3 that I worked toward an ethic of transparency in collecting and analyzing data throughout my relationships with hospice caregiver participants. This approach buffered threats that my own subjectivity may hold for the trustworthiness of the study findings, as participants provided ongoing feedback on my analyses and interpretations. Further, during the study process I reflected on my findings with audiences external to the hospice context, soliciting assessments as to the relevance, meaningfulness, and credibility of my thinking. This included informal conversations with clinical and academic members of the palliative care community (e.g., at professional meetings and conferences) as well as a more formal presentation that I gave in April 2011 (four months before completing fieldwork) at the University of Ottawa. In this presentation I discussed and received feedback on preliminary findings with an audience of nurses with clinical and research experience in palliative care.

As with any study that relies on observation of clinical practice, I cannot be certain of the ways that participants may have altered their typical patterns of behaviour, cognizant of the fact they were being observed. I believe however that such misrepresentations would likely have become visible to me after repeated field visits over a prolonged period of time. Further, my interpretations of hospice caregiving practice are not based solely on observing or talking with individual clinicians. Rather, I drew on a multitude of sources that provided for a triangulation of perspectives, building toward an overall interpretation of the driving ethos and daily practices of caregivers in this setting. Such sources included documentary evidence that predate my commencement of the project, as well as observing group interactions amongst

caregivers, patients, and families. Further, talking with patients and families about their experiences of hospice validated the caregiving practices that I observed, and minimized the likelihood that these were merely being 'performed' for the benefit of this research.

Implications for Nursing

Hospice caregivers in this study showed a strong commitment to personal and professional values related to the good death, and yet simultaneously demonstrated a reflective awareness around working with patients and families whose own circumstances of dying and death conflicted with some of their own assumptions. Their thinking about delirium and their response to delirious patients and their families were best understood through concomitant analysis of the cultural ethos of this setting: creating a safe place for the good death to occur. Their clinical engagement with the concept of delirium happened through a broad orientation toward developing helpful and supportive relationships with patients and families, whereby questions of comfort, perceived safety, and minimization of distress were the top priorities. Based on these findings, I suggest the following implications for nursing practice and education:

1. The need for reflective awareness: Therapeutic relationships in EOLC require that as caregivers, we acknowledge the values we bring to the relational encounter, and that we reflect on the degree to which we expect our patients and their families to abide by these values.
2. The need for a cultural analysis: Attempts to improve end-of-life delirium care in local care contexts will be facilitated through an exploration of the cultural orientation of that care environment.
3. The need for a relational ethic: Care of delirious patients and their families toward their good death is best fostered through a relational caregiving ethic that conceives of and responds to delirium as a holistic human experience.

Reflective awareness.

According to Wilson, Fillion, et al (2009) the notion of a good death is widely used but loosely defined. This, I suspect, is a good thing. The moral tenability of the good death construct depends on its ability to adequately orient us toward the values and preferences that patients and families have for their own end-of-life experiences,

without going so far as to become a constrictive force on other people's lives (Wright & Pugnaire Gros, 2012). The good death is a "values-based concept" and is determined by the people, context, and circumstances of each individual case (Wilson, Fillion et al., p. 28). As Roy (2012) aptly highlights, the idea that there is only one correct way to die is an "untruth" (p. 4) about palliative care.

The need for reflective practice amongst end-of-life caregivers is particularly salient, given the reported challenge that clinicians face in working with patients and families who do not 'accept' or acknowledge the end-of-life nature of their current circumstance (Thompson et al., 2006; Zimmermann, 2012). According to a grounded theory study about reconciling decisions near the end-of-life, Norton and Bowers (2001) describe a process by which EOLC providers work to change treatment decisions that they view as unrealistic and inappropriate (curative) toward decisions that they view as more realistic and appropriate (palliative). The processes by which caregivers in that study engaged in reconciling such decisions were remarkably consistent with what I identified as *bringing families on board* in my study. Specifically, Norton and Bowers reported that "changing the patient's or proxy's understanding, that is, their 'big picture,' to one in accord with the providers' assessment led the patient and family to realistic goals and thus to palliative treatment choices" (p. 262). In their discussion of these findings, these authors wrestle with interpreting these processes as caring and supportive, or as paternalistic and coercive. On the one hand, end-of-life caregivers have an obligation to help patients and families through a challenging situation for which they lack the necessary knowledge and expertise necessary for successful navigation. Conversely, imposing one's own agenda on a patient or family in EOLC risks an affront to that person's autonomy and alienation in the caring relationship. Norton and Bowers however caution that to reduce these findings to a binary of paternalism versus autonomy would betray the complex realities of caregivers' roles in supporting decision-making in the end-of-life context. Indeed, sociological study of patients' perspectives on dying and being cared for in hospice illustrate that "moral practices of 'dying well' and 'caring well', and how these are done by different actors, reflect constraint *and* agency, choice *and* the pressures of normative values" (Broom & Cavenagh, 2010, p. 875, original emphasis). Regarding the

tension between paternalism and autonomy, Norton and Bowers advocate for a reflective practice, whereby:

Providers often have access to knowledge and experiences that patients and families do not. Deciding how best to share this knowledge and experience with patients and families requires that providers carefully examine their own motives and beliefs about death and dying. (p. 268)

Thus, processes such as *bringing families on board* are not inherently problematic for ethical practice in EOLC. Indeed, many families in this study appeared to have a need for guidance from hospice caregivers in how to structure their moral experience of their time in hospice. These families seemed to benefit immensely when caregivers provided them with such structure. The implication I am suggesting is that by making such processes explicit, we can become more aware of how our own values and approaches shape the relational encounter. This will help us engage in respectful and supportive relationships with patients and families whose own perspectives are less familiar to us. Such perspectives might include families who desire to situate themselves as co-workers rather than clients in EOLC (Stajduhar et al., 2008), and/or families who for whatever reason resist acknowledging and engaging with the reality of impending death (James et al., 2007; Quill, Arnold, & Back, 2009; Sjolander, Hedberg, & Ahlstrom, 2011). A reflective awareness of our own perspectives in such situations will provide helpful insight into how to foster mutuality in the caregiving encounter (Hartrick, 1997; Tarlier, 2004) and can inspire ethically responsive ways to navigate the relationships that challenge us (Austin et al., 2009). A reflective practice concerning the potential tension between paternalism and autonomy within EOLC relationships might start with the questions posed by Josselson (1996) concerning what she calls the “enigmas” of care (p. 222). Specifically: “How do we hold without suffocating? How do we teach without imposing? How do we bring our passion to others without overwhelming them? How do we touch, how do we participate fully with another tenderly, without doing harm?” (p. 222).

In recognizing the significance that our own values will play in shaping the relational encounter in EOLC, we are compelled to consider innovative strategies in pre-licensure as well as continuing professional education. Such strategies should draw

forth the reflective capacities of nurses and other members of the interprofessional team. For example, Brajtman, Hall and Barnes (2009) describe an undergraduate course in which students from nursing and other health professions read popular literature about death and dying, and write reflective focus notes in response to these readings. They then share their reflections with students and faculty in small-group seminar formats. In this way, personal values that students have about working with the dying are drawn forth for critique and challenge by peers. Students are thus helped to recognize the significance that their own values will have for the relationships they form with patients and families in clinical practice. Similarly, strategies for practicing nurses might include the facilitation by nursing leadership of reflective discussion groups within the clinical setting, such that team members can come together to strengthen their practice around ideals of person and family-centered care (Wright & Pugnaire-Gros, 2010).

Cultural analysis.

Readers of this research may be interested in considering how nurses in their own settings conceive of, assess, and manage delirium at the end of life. My findings demonstrate that the nursing approach to end-of-life delirium is culturally bound, i.e., driven by the broader values and priorities of hospice caregiving practice. Therefore, while the specific results of this study are not necessarily transferable to other contexts, the multitude ways in which delirium care and good death practice were found to interact can effectively guide others to ask important questions of their own care contexts. The implication here is that for others who are hoping to examine and improve nursing care practices concerning delirium at the end of life, consideration of the following questions will prove helpful: What does a good death mean here, for these nurses and other professional caregivers? What do ideas of whole-person and family-centered care mean in this setting? How do caregivers in this setting conceive of suffering, wellbeing, and the relationship of the physical and mental realms of human experience in dying? What is the degree of interprofessional collaboration here? Do nurses and other caregivers share similar conceptions of what delirium means, and its implications for the end-of-life experience of patient and family? How are patients typically *known* in this particular setting? What is at stake for the good death when

manifestations of delirium appear to be an issue here?

Relational ethic.

In our current era of evidence-based practice, we are striving toward consistency of definition for delirium and the standardization of clinical approaches to assessment and management, which we assume will improve practice (Leonard et al., 2008). This is thought to be a particularly pressing need given the widespread concern that currently, many patients with delirium are missed (i.e., not identified) and thus receive inadequate care (Barnes, Kite, & Kumar, 2010; Rao, Ferris, & Irwin, 2011; Rice et al., 2011; Smith & Adcock, 2011). Studies of nursing practice conclude that nurses often cannot identify the core features of delirium in their patients, that they fail to make use of the notion of delirium in their clinical language and reasoning, and that they are conducting superficial mental status assessments (Inouye et al., 2001; Steis & Fick, 2008). This is all cause for great concern, with multiple authors sounding an alarm of ethical concern for the wellbeing of delirious patients perceived to be neglected through substandard nursing (Dahlke & Phinney, 2008; Kjørven, 2009). According to Agar et al (2012), who interviewed forty nurses about their perspectives on delirium assessment and management, the problem is that nurses are not contextualizing their assessments and observations of patients within a “delirium definitional framework” (p. 8). The conventional wisdom is that if nurses in practice could be better sensitized to the concept of delirium, i.e., if they can recognize the core features of delirium for what they are and the importance of these for patient wellbeing, they will be primed to better observe for, identify, and respond to situations of delirium as a routine and integral aspect of their everyday work (Day, Higgins, & Koch, 2009).

To a certain extent, the findings of my study support the importance of increasing nurses’ awareness of delirium. Hospice nurses were self-critical about the relative lack of a delirium definitional framework in their work. They further suggested that adopting such a framework might have beneficial implications for delirium care, both in terms of palliation and reversal. At the same time, however, the findings of my study showed that conceptions of nurse “recognition” or “identification” of delirium are alone insufficient to understand the complex ways in which nurses in EOLC promote the mental wellbeing of their dying patients. Specifically, I found that while nurses may not

always use the word delirium in everyday practice, their assessments and responses to patients in mental distress are nevertheless complex and sophisticated. Nurses in my study worked toward a balanced perspective between acknowledging cognitive impairment as a potential feature of normal dying, while recognizing it as an area of important concern for their patients' wellbeing. To this end, they were less concerned with diagnosing patients as delirious than with identifying patients for whom mental state was a source of distress.

In a thought-provoking article by Cameron (2006) about the "unpresentable" aspects of nursing practice, a case study is provided about a terminally ill patient in hospital who becomes delirious overnight. Cameron describes the dialogue that occurs the following morning between the night nurse and the day nurses during change-of-shift report. In their discussion, these nurses do not use the word delirium. Nevertheless, they systematically consider various medical hypotheses that might explain the mental status change observed, and they implement various pharmacological and non-pharmacological interventions in response. In essence, their practice successfully mirrors our current knowledge of best practice in end-of-life delirium care (Brajtman et al., 2011). At the same time, the nurses interpret the patient's delirious experience through what they know about him *as a person*. Specifically, they venture hypotheses about the meaning of the delirious experience in the context of what they know of his relationship with his wife and of his current feelings concerning his diagnosis and impending death. About this case, Cameron concludes that:

At first sight we could say that this is a man with an episode of delirium. Yet this is the first layer to understand the text of this situation, an initial albeit necessary approximation only. If we stayed with this layer alone, we would be unable to understand the interwovenness of the many texts present here...Mr Phillips' nurse is able through her present engagement to see the hidden texts that lie behind this delirium. (p. 28)

A relational caregiving ethic to guide delirium practice in end-of-life settings encourages the nurse to engage the many "texts" that are present in any individual situation. Within a relational caregiving ethic, the central nursing preoccupation is not whether or not the patient evidences a particular medical diagnosis, i.e., delirium, but

rather the extent to which he or she is distressed or comfortable, and the various sources of influence underlying the patient's wellbeing. A relational caregiving ethic guides the nurse in considering basic questions about the patient's experience, questions such as: How is the patient doing today? Is he or she himself or herself? How do I know? Within a relational caregiving ethic, nursing responses to delirious experiences that are *not* a source of suffering are better understood. Further, a relational ethic orients the nurse in considering what is unique about this person with delirium and his or her family, at this time, and in this place, i.e., *what are the values, priorities, and goals that are relevant in this particular situation?*

In these ways, responses to delirium in EOLC can be accommodated within a broader goal of providing for the patient and family's good death. Providing for another's good death in EOLC necessarily evades standardization, and instead requires a personalized and situation-responsive nursing practice. The standardization approach encourages nurses to structure their clinical reasoning around observable facts, questioning *how does this clinical picture fit with other typical pictures of delirium?* Conversely, the theoretical and practice legacy of nursing's disciplinary history encourages a narrative form of clinical reasoning (Sakalys, 2003), questioning *in what ways is this (delirious) patient's situation unique?* What the hospice caregivers in my study have demonstrated, like the nurses in Cameron's depiction, is that it is possible and desirable to adopt an evidence-based approach to palliative delirium care, i.e., screen for occurrence, identify the cause, reverse if possible and appropriate, and treat the symptoms, within a more holistic practice that analyzes and responds to the meanings the apparent delirium experience holds for the lived experience of the individual and family.

Directions for Future Research

Because of the nature of the relationships that they form with their patients, for example by being at the bedside at all hours of the day and night and by providing intimate bodily care, nurses are uniquely positioned within the interprofessional team in coming to know important dimensions of the patient's lived experience of terminal illness (Wright & Brajtman, 2011). Findings from this study further support the idea that nurses have an important role to play in helping other members of the

interprofessional team understand the nature of patient and family experiences. Specifically, processes of relational engagement with patient and family and continuous team communication enabled coming to know the patient's typical patterns and behaviours. This facilitated identification of patients who might be delirious (i.e., not themselves) and an interpretation of the significance of the delirium for the patient's overall wellbeing (i.e., distressed or comfortable). In this setting, because all hospice caregivers shared a common vision for the good death and a common language in speaking about patients with delirium, cultural divides between different professions were not a problem for collaborative, interprofessional practice. This hospice, however, is not representative of other care contexts in which differences in health professional socialization limits clinicians' abilities to engage with each other and promote holistic, patient-centered care (Pippa Hall, 2005). For example, in this setting the variable use of a delirium definitional framework in nursing practice was counterbalanced by a narrative engagement with the patient's mental state that was welcomed and understood by other caregivers, e.g., psychologist, social worker, physicians. In other settings however, different professions may not be as familiar with such an approach, which would make efforts by nurses to advocate for the holistic care of their delirious patients more difficult. Thus, future studies of end-of-life delirium should examine how nurses practice, reason, and collaborate with other members of the interprofessional team, specifically with respect to processes of assessing and managing delirium at the end of life.

In my study, delirium was found to complicate the good death practice of hospice caregivers in two different ways, both of which have been highlighted in other literature. First, when patients show signs of delirium close to death, caregivers are often thrust into uncertainty about whether efforts directed at reversal are appropriate (LeGrand, 2012). Second, the administration of pain medications, e.g., opioids, is a source of ambivalence for some families who equate the onset of delirium symptoms with inappropriate administration of such medications (Cohen et al., 2009). Future research might begin with tensions such as these, exploring them with more focus and depth than has previously been done. Specifically, what does end-of-life delirium care look like in settings where caregivers, families, and patients themselves do not

interpret the ideals of the good death in the same way as participants in my study did? The importance for such research is particularly relevant given that in this study, it is possible that I enjoyed preferential access to patients and families who were the *most* satisfied with their hospice experience and the hospice caregiving philosophy. As described in Chapter 3, my relationships with patients and families were entirely dependent on their willingness to engage with me. Thus, it is possible that families who were dissatisfied might have been less likely to speak with me, and that their 'voice' is underrepresented in this study. In this project, I did not explore in depth a dissenting perspective amongst patients or families for whom the hospice approach to care is not a good 'fit' with their needs or interests (Wright & Pugnare-Gros, 2012). I did however catch glimpses of such situations, for example the family who believed that morphine was the source of their loved one's delirium and who seemed mistrustful of hospice caregivers as a result. Therefore, a more focused and deliberate engagement with the perspectives of patients and families whose concerns and interests do not align with the overarching approach of hospice care is an important area for future research in this field.

Concluding Statements

Helping terminally ill patients to reach a peaceful and dignified death is recognized as a core value of ethical nursing practice (CNA, 2008a). In this study, I found that the architectural layout and social fabric of the hospice setting creates an intimate environment that provides a safe context for dying. In this setting patients and families feel known and cared about. Hospice caregivers build relationships with patients and families that are oriented toward overcoming the disengagement that is characteristic of much of modern healthcare (Austin, 2006; Schultz & Carnevale, 1996). They are here to offer supportive presence and a helping hand to people as they die, or as they watch someone they love die.

The people who work and volunteer here share a piece of what they have created. They are committed to a vision for what health in dying can mean. They are dismayed at the lack of helpful support that dying patients and families experience under a paradigm of mainstream biomedicine, and have actively constructed a counterculture in which values of comfort, peacefulness, relationship, and dignity prevail. They have cultivated a collective wisdom about the significance of dying and death on the moral experience of being human. They have established cultural norms of practice around facilitating good deaths, within which specific approaches to conceptualizing, assessing, and managing end-of-life delirium are subsumed.

In designing this study and entering this hospice, I was skeptical about the ways in which notions of good death were sustainable in a context of end-of-life delirium, as the attributes of each appeared to me irreconcilable. Instead, I found that from the perspective of hospice caregivers, the delirious death does not necessarily imply a bad death here. Rather, experiences of conscious and cognitive change in dying are woven by hospice caregivers into a coherent system of meaning that is accommodated into prevailing scripts of what it means to die well. Further, I found that delirium itself provides a context whereby processes of supporting families through the death of the patient are enabled.

As a palliative care nurse, the experience of conducting this research caused me to reflect on my own practice, and changed the ways that I interact with my patients, their

families, and my colleagues. For example, I now more regularly reflect about whether my patients seem ‘themselves’ at any given moment, and when I cannot answer this question because I do not yet *know* a patient, I seek input from my colleagues. I now counsel families with greater confidence around the commonality of changes in consciousness and cognition in dying, and have observed them to respond positively to my efforts of validating and normalizing their questions, feelings, and concerns. Further, I have become intrigued by notions of delirium-as-wellness and delirium-as-change, and am now more likely to *hear* my patients when they speak of their own deaths using metaphorical language. For example, conducting this research has changed the way I will engage with a restless patient who is near death and insisting that she needs to go “home.” Finally, as a nursing teacher, my experience conducting this study has inspired ways of guiding my students to grasp the complexity inherent to their own clinical situations. For example, in mentoring undergraduate students in their care of cognitively impaired older adults, I push them to be curious about and to discover the multiple layers that characterize their patients’ experience, i.e., the multiple *texts* as described by Cameron (2006). Further, I encourage them to realize that despite their initial impressions of patients who might seem *unreachable* due to cognitive deterioration, engaging and creating “moments of connection” with such patients is a reasonable and important goal.

I hope that nurses who read this research will likewise be inspired to think about their practice. According to Saunders (2006), nurses “remain the core of the personal and professional drive to enable people to find relief, support, and meaning at the end of their lives” (p. v). I believe that if we pay consistent and meticulous attention to the mental wellbeing of our patients, we can better respond to this moral imperative. In EOLC, we encounter patients and their families during the most “poignant moments” of their lives (Ferrell & Coyle, 2008, p. 242), and as such we play an important role in shaping how they live their final experiences together. The nursing that we deliver in the final months, days, hours, and minutes of someone’s life become part of the stories that are told and retold by family as they construct and live their bereavement. In grasping the complex ways in which delirium and good death practice interrelate, we are better positioned to create safe places for patients and families to receive end-of-

life care; to help them to “hold to the light around and within them, for as long as they have life” (Nelson, 2000, p. 39).

References

- Abernethy, A. P., & Wheeler, J. L. (2008). Total dyspnoea. *Current Opinion in Supportive and Palliative Care*, 2(2), 110-113.
- Abma, T. A. (2005). Struggling with the fragility of life: a relational-narrative approach to ethics in palliative nursing. *Nursing Ethics*, 12(4), 337-348.
- Adamis, D., Treloar, A., Martin, F. C., & Macdonald, A. J. D. (2007). A brief review of the history of delirium as a mental disorder. *History of Psychiatry*, 18(4), 459-469.
- Addington-Hall, J. (2002). Research sensitivities to palliative care patients. *European Journal of Cancer Care*, 11, 220-224.
- Agar, M., Draper, B., Phillips, P. A., Phillips, J., Collier, A., Harlum, J., & Currow, D. (2012). Making decisions about delirium: a qualitative comparison of decision making between nurses working in palliative care, aged care, aged care psychiatry, and oncology. *Palliative Medicine*, 26, 887-896.
- Alici, Y., & Breitbart, W. (2009). Delirium in palliative care. *Primary Psychiatry*, 16(5), 42-48.
- Allan, H. T. (2006). Using participant observation to immerse oneself in the field. *Journal of Research in Nursing*, 11(5), 397-407.
- Allen, D. (2004). Ethnomethodological insights into insider-outsider relationships in nursing ethnographies of healthcare settings. *Nursing Inquiry*, 11(1), 14-24.
- Allmark, P. (2003). Popper and nursing theory. *Nursing Philosophy*, 4, 4-16.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-text revised* (4th ed.). Washington, DC.
- American Psychiatric Association. (2012). DSM-5 Development. Retrieved August 10 2012, from <http://www.dsm5.org/ProposedRevision/Pages/proposedrevision.aspx?rid=32>
- Anderberg, P., Lepp, M., Berglund, A., & Segesten, K. (2007). Preserving dignity in caring for older adults: a concept analysis. *Journal of Advanced Nursing*, 59(6), 635-643.
- Andersson, E. M., Norberg, A., & Hallberg, I. R. (2002). Acute confusional episodes in elderly orthopaedic patients: the patients' actions and speech. *International Journal of Nursing Studies*, 39, 303-317.
- Appleton, J., & King, L. (1997). Constructivism: a naturalistic methodology for nursing inquiry. *Advances in Nursing Science*, 20(2), 13-22.
- Atkinson, P. (1992a). *Understanding ethnographic texts*. Newbury Park, CA: Sage Publications.
- Atkinson, P. (1992b). The ethnography of a medical setting: reading, writing, and rhetoric. *Qualitative Health Research*, 2, 451-474.
- Atkinson, P., Coffey, A., & Delamont, S. (2003). *Key themes in qualitative research*. Walnut Creek, CA: Altamira Press.
- Austin, W. (2006). Engagement in contemporary practice: a relational ethics perspective. *Texto Contexto Enferm (Florianopolis)*, 15(Esp), 135-141.
- Austin, W. (2007). The ethics of everyday practice: healthcare environments as moral communities. *Advances in Nursing Science*, 30(1), 81-88.

- Austin, W., Goble, E., Strang, V., Mitchell, A., Thompson, E., Lantz, H., . . . Vass, K. (2009). Supporting relationships between family and staff in continuing care settings. *Journal of Family Nursing*, 15(3), 360-383.
- Austin, W. J. (2011). The incommensurability of nursing as a practice and the customer service model: an evolutionary threat to the discipline. *Nursing Philosophy*, 12, 158-166.
- Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal*, 322, 1115-1117.
- Barnes, J., Kite, S., & Kumar, M. (2010). The recognition and documentation of delirium in hospital palliative care inpatients. *Palliative and Supportive Care*, 8, 133-136.
- Baumbusch, J. L. (2011). Conducting critical ethnography in long-term residential care: experiences of a novice researcher in the field. *Journal of Advanced Nursing*, 67(1), 184-192.
- Beagan, B., & Ells, C. (2007). Values that matter, barriers that interfere: the struggle of Canadian nurses to enact their values. *Canadian Journal of Nursing Research*, 39(4), 36-57.
- Becker, H. S., & Geer, B. (1957). Participant observation and interviewing: a comparison. *Human Organization*, 16, 28-32.
- Belanger, L., & Ducharme, F. (2011). Patients' and nurses' experiences of delirium: a review of qualitative studies. *Nursing in Critical Care*, 16(6), 303-315.
- Benner, P. (2000). The roles of embodiment, emotion and lifeworld for rationality and agency in nursing practice. *Nursing Philosophy*, 1, 5-19.
- Bergum, V. (2004). Relational ethics in nursing. In J. L. Storch, P. Rodney & R. Starzomski (Eds.), *Toward a moral horizon: nursing ethics for leadership and practice* (pp. 485-503). Toronto, ON: Pearson Canada Inc.
- Bergum, V. (2013). Relational ethics for health care. In J. L. Storch, P. Rodney & R. Starzomski (Eds.), *Toward a moral horizon: nursing ethics for leadership and practice* (2nd ed., pp. 127-142). Toronto, ON: Pearson Canada Inc.
- Bergum, V., & Dossetor, J. (2005). *Relational ethics: the full meaning of respect*. Hagerstown, MD: University Publishing Group.
- Berrios, G. E. (1999). 'Délire': in Encyclopédie ou dictionnaire raisonné des sciences, des arts, et des métiers (Volume 4, 1754) DIDEROT et d'ALEMBERT. *History of Psychiatry*, 10, 536-541.
- Berry, P., & Griffie, J. (2006). Planning for the actual death. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of palliative nursing* (2nd ed., pp. 561-577). New-York, NY: Oxford University Press.
- Blanchette, H. (2005). Assessment and treatment of terminal restlessness in the hospitalized adult patient with cancer. *Medsurg Nursing*, 14(1), 17-22.
- Bland, M. (2007). Betwixt and between: a critical ethnography of comfort in New Zealand residential aged care. *Journal of Clinical Nursing*, 16, 937-944.
- Bloom, L. R. (1998). *Under the sign of hope: feminist methodology and narrative interpretation*. New-York, NY: State University of New-York Press.
- Boyle, D. A. (2006). Delirium in older adults with cancer: implications for practice and research. *Oncology Nursing Forum*, 33(1), 61-78.
- Brajtman, S. (2003). The impact on the family of terminal restlessness and its management. *Palliative Medicine*, 17, 454-460.

- Brajtman, S. (2005a). Helping the family through the experience of terminal restlessness. *Journal of Hospice and Palliative Nursing*, 7(2), 73-81.
- Brajtman, S. (2005b). Terminal restlessness: perspectives of an interdisciplinary palliative care team. *International Journal of Palliative Nursing*, 11(4), 170-178.
- Brajtman, S., Hall, P., & Barnes, P. (2009). Enhancing interprofessional education in end-of-life care: an interdisciplinary exploration of death and dying in literature. *Journal of Palliative Care*, 25(2), 125-131.
- Brajtman, S., Higuchi, K., & McPherson, C. (2006). Caring for patients with terminal delirium: palliative care unit and home care nurses' experiences. *International Journal of Palliative Nursing*, 12(4), 150-156.
- Brajtman, S., Wright, D., Hogan, D. B., Allard, P., Bruto, V., Burne, D., . . . Wilson, K. (2011). Developing guidelines on the assessment and treatment of delirium in older adults at the end of life. *Canadian Geriatrics Journal*, 14(2), 40-50.
- Brayne, S., Farnham, C., & Fenwick, P. (2006). Deathbed phenomena and their effect on a palliative care team: a pilot study. *American Journal of Hospice & Palliative Medicine*, 23(1), 17-24.
- Brayne, S., Lovelace, H., & Fenwick, P. (2008). End-of-life experiences and the dying process in a Gloucestershire nursing home as reported by nurses and care assistants. *American Journal of Hospice & Palliative Medicine*, 25(3), 195-206.
- Breaden, K., Hegarty, M., Swetenham, K., & Grbich, C. (2012). Negotiating uncertain terrain: a qualitative analysis of clinicians' experiences of refractory suffering. *Journal of Palliative Medicine*, 15(8), 1-6.
- Breitbart, W., & Alici, Y. (2008). Agitation and delirium at the end of life: "We couldn't manage him". *Journal of the American Medical Association*, 300(24), 2898-2910.
- Breitbart, W., & Alici, Y. (2012). Evidence-based treatment of delirium in patients with cancer. *Journal of Clinical Oncology*, 30(11), 1206-1214.
- Breitbart, W., & Cohen, K. (2000). Delirium in the terminally ill. In H. M. Chochinov & W. Breitbart (Eds.), *Handbook of psychiatry in palliative medicine* (pp. 75-90). New-York, NY: Oxford University Press.
- Breitbart, W., Gibson, C., & Tremblay, A. (2002). The delirium experience: delirium recall and delirium-related distress in hospitalized patients with cancer, their spouses/caregivers, and their nurses. *Psychosomatics*, 43, 183-194.
- Breitbart, W., & Strout, D. (2000). Delirium in the terminally ill. *Clinics in Geriatric Medicine*, 16(2), 357-372.
- Brink, P. J., & Edgecombe, N. (2003). What is becoming of ethnography? *Qualitative Health Research*, 13(7), 1028-1030.
- Broom, A., & Cavenagh, J. (2010). Masculinity, moralities and being cared for: an exploration of experiences of living and dying in a hospice. *Social Science & Medicine*, 71, 869-876.
- Brown, S., & Degner, L. F. (2001). Delirium in the terminally-ill cancer patient: aetiology, symptoms and management. *International Journal of Palliative Nursing*, 7(6), 270-272.
- Brown, T. (2010). *Critical care: a new nurse faces death, life, and everything in between*. New-York, NY: HarperCollins.

- Bruce, A., & Boston, P. (2008). The changing landscape of palliative care: emotional challenges for hospice palliative care professionals. *Journal of Hospice and Palliative Nursing*, 10(1), 49-55.
- Bruce, A., Schreiber, R., Petrovskaya, O., & Boston, P. (2011). Longing for ground in a ground(less) world: a qualitative inquiry of existential suffering. *BMC Nursing*, 10(2). doi: 10.1186/1472-6955-10-2
- Bruera, E. (1994). Ethical issues in palliative care research. *Journal of Palliative Care*, 10(3), 7-9.
- Bruera, E., Bush, S. H., Willey, J., Paraskevopoulos, T., Li, Z., Palmer, J. L., . . . Elsayem, A. (2009). Impact of delirium and recall on the level of distress in patients with advanced cancer and their family caregivers. *Cancer*, 115, 2004-2012.
- Bush, S. H., & Bruera, E. (2009). The assessment and management of delirium in cancer patients. *The Oncologist*, 14(10), 1039-1049.
- Buss, M. K., Vanderwerker, L. C., Inouye, S. K., Zhang, B., Block, S. D., & Prigerson, H. G. (2007). Associations between caregiver-perceived delirium in patients with cancer and generalized anxiety in their caregivers. *Journal of Palliative Medicine*, 10(5), 1083-1092.
- Byock, I. (1994). When suffering persists. *Journal of Palliative Care*, 10(2), 8-13.
- Byock, I. (1996). The nature of suffering and the nature of opportunity at the end of life. *Clinics in Geriatric Medicine*, 12(2), 237-252.
- Byock, I. (1997). *Dying well: the prospect for growth at the end of life*. New-York, NY: Riverhead Books.
- Byock, I. (2002). The meaning and value of death. *Journal of Palliative Medicine*, 5(2), 279-288.
- Byock, I. (2004). *The four things that matter most: a book about living*. New-York, NY: Simon & Schuster.
- Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud': toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, 2(2), Article 1. Retrieved from <http://www.ualberta.ca/~iiqm/backissues/pdf/caellietal.pdf>
- Cairns, M., Thompson, M., & Wainwright, W. (2003). *Transitions in dying and bereavement: a psychosocial guide for hospice and palliative care*. Winnipeg, MB: Health Professions Press.
- Callanan, M. (2008). *Final journeys: a practical guide for bringing care and comfort at the end of life*. New-York, NY Bantam Dell.
- Callanan, M., & Kelley, P. (1992). *Final gifts: understanding the special awareness, needs, and communications of the dying*. New-York, NY: Bantam Dell.
- Cameron, B. L. (2006). Towards understanding the unrepresentable in nursing: some nursing philosophical considerations. *Nursing Philosophy*, 7, 23-35.
- Campbell, J. C., & Bunting, S. (1999). Voices and paradigms: perspectives on critical and feminist theory in nursing. In E. C. Polifroni & M. Welch (Eds.), *Perspectives on philosophy of science in nursing: an historical and contemporary anthology* (pp. 411-422). Philadelphia, PA: Lippincott.
- Campbell, R., & Wasco, S. M. (2000). Feminist approaches to social science: epistemological and methodological tenets. *American Journal of Community Psychology*, 28(6), 773-791.

- Canadian Coalition for Seniors Mental Health. (2006). National guidelines for seniors' mental health: the assessment and treatment of delirium. Toronto, ON.
- Canadian Hospice Palliative Care Association Nursing Standards Committee. (2009). Canadian hospice palliative care nursing standards of practice Retrieved August 8, 2012, from http://www.chpca.net/interest_groups/nurses_ig.html
- Canadian Nurses Association. (2008a). Code of ethics for registered nurses. Ottawa, ON.
- Canadian Nurses Association. (2008b). Advanced nursing practice: a national framework. Ottawa, ON.
- Caraceni, A., & Bosisio, M. (2004). Acute confusional state. In R. Voltz, J. L. Bernat, G. D. Borasio, I. Maddocks, D. Oliver & R. K. Portenoy (Eds.), *Palliative care in neurology* (pp. 228-240). New-York, NY: Oxford University Press.
- Caraceni, A., & Grassi, L. (2011). *Delirium: acute confusional states in palliative medicine* (2nd ed.). New-York, NY: Oxford University Press.
- Caraceni, A., & Simonetti, F. (2009). Palliating delirium in patients with cancer. *Lancet Oncology*, 10(164-172).
- Caraceni, A., Zecca, E., Martini, C., Gorni, G., Campa, T., Brunelli, C., & De Conno, F. (2012). Palliative sedation at the end of life at a tertiary cancer center. *Supportive Care in Cancer*, 20, 1299-1307.
- Carlander, I., Ternestedt, B., Sahlberg-Blom, E., Hellstrom, I., & Sandberg, J. (2011). Four aspects of self-image close to death at home. *International Journal of Qualitative Studies in Health and Well-being*, 6(5931). doi: 10.3402/qhw.v6i2.5931
- Carnevale, F. A. (2002). Authentic qualitative research and the quest for methodological rigour. *Canadian Journal of Nursing Research*, 34(2), 121-128.
- Carnevale, F. A. (2005). Ethical care of the critically ill child: a conception of a 'thick' bioethics. *Nursing Ethics*, 12(3), 239-252.
- Carnevale, F. A., & Weinstock, D. M. (2011). Questions in contemporary medicine and the philosophy of Charles Taylor: an introduction. *Journal of Medicine and Philosophy*, 36, 329-334.
- Carolan, M., Andrews, G. J., & Hodnett, E. (2006). Writing place: a comparison of nursing research and health geography. *Nursing Inquiry*, 13(3), 203-219.
- Carper, B. A. (2004[1978]). Fundamental patterns of knowing in nursing. In P. G. Reed, N. C. Shearer & L. H. Nicoll (Eds.), *Perspectives on Nursing Theory* (4th ed., pp. 221-228). Philadelphia, PA: Lippincott Williams & Wilkins.
- Casey, D., Murphy, K., Ni Leime, A., Larkin, P., Payne, S., Froggatt, K. A., & O'Shea, E. (2011). Dying well: factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland. *Journal of Clinical Nursing*, 20, 1824-1833.
- Cassarett, D. J., & Inouye, S. K. (2001). Diagnosis and management of delirium near the end of life. *Annals of Internal Medicine*, 135, 32-40.
- Cassell, E. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, 306(11), 639-645.
- Cassell, E. J. (2007). Unanswered questions: bioethics and human relationships. *The Hastings Center Report*, 37(5), 20-23.
- Centeno, C., Sanz, A., & Bruera, E. (2004). Delirium in advanced cancer patients. *Palliative Medicine*, 18, 184-194.

- Cerejeira, J., & Mukaetova-Ladinska, E. B. (2011). A clinical update on delirium: from early recognition to effective management. *Nursing Research and Practice*. doi: 10.1155/2011/875196
- Chan, L. S., Macdonald, M. E., & Cohen, S. R. (2009). Moving culture beyond ethnicity: examining dying in hospital through a cultural lens. *Journal of Palliative Care*, 25(2), 117-124.
- Chinn, P. L. (1997). Methodolatry? *Advances in Nursing Science*, 20(2), vi.
- Chochinov, H. M. (2002). Dignity conserving care - a new model for palliative care: helping the patient feel valued. *Journal of the American Medical Association*, 287, 2253-2260.
- Chochinov, H. M. (2007). Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *British Medical Journal*, 335, 184-187.
- Chochinov, H. M., Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2002). Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine*, 54(3), 433-443.
- Claessens, P., Genbrugge, E., Vannuffelen, R., Broeckaert, B., Schotsmans, P., & Menten, J. (2007). Palliative sedation and nursing: the place of palliative sedation within palliative nursing. *Journal of Hospice and Palliative Nursing*, 9(2), 100-108.
- Clark, D. (1999). 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Social Science & Medicine*, 49, 727-736.
- Clark, D. (2002). Between hope and acceptance: the medicalisation of dying. *British Medical Journal*, 324, 905-907.
- Clark, D. (2007). From margins to centre: a review of the history of palliative care in cancer. *Lancet Oncology*, 8, 430-438.
- Clark, D., & Seymour, J. (1999). *Reflections on palliative care*. Philadelphia, PA: Open University Press.
- Clark, J. (2003). Patient centred death. *British Medical Journal*, 327, 174-175.
- Cohen, M. Z., Pace, E. A., Kaur, G., & Bruera, E. (2009). Delirium in advanced cancer leading to distress in patients and family caregivers. *Journal of Palliative Care*, 25(3), 164-171.
- Copp, G. (1997). Patients' and nurses' constructions of death and dying in a hospice setting. *Journal of Cancer Nursing*, 1(1), 2-13.
- Corr, C. A. (2007). Hospice: achievements, legacies, and challenges. *Omega - Journal of Death and Dying*, 56(1), 111-120.
- Costello, J. (2001). Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *Journal of Advanced Nursing*, 35(1), 59-68.
- Coward, H., & Stajduhar, K. I. (Eds.). (2012). *Religious understandings of a good death in hospice palliative care*. Albany, NY: State University of New-York Press.
- Cramer, C. F. (2010). To live until you die: quality of life at the end of life. *Clinical Journal of Oncology Nursing*, 14(1), 53-56.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Cronqvist, A., Theorell, T., Burns, T., & Lutzen, K. (2004). Caring about - caring for: moral obligations and work responsibilities in intensive care nursing. *Nursing Ethics*, 11(1), 63-76.

- Cutcliffe, J. R., & McKenna, H. P. (2002). When do we know that we know? Considering the truth of research findings and the craft of qualitative research. *International Journal of Nursing Studies*, 39(6), 611-618.
- Dahlke, S., & Phinney, A. (2008). Caring for hospitalized older adults at risk for delirium: the silent, unspoken piece of nursing practice. *Journal of Gerontological Nursing*, 34(6), 41-47.
- Davies, B. (2006). Supporting families in palliative care. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of Palliative Nursing* (2nd ed., pp. 545-560). New-York, NY: Oxford University Press.
- Davies, B., & Oberle, K. (1990). Dimensions of the supportive role of the nurse in palliative care. *Oncology Nursing Forum*, 17(1), 87-94.
- Davies, E., Higginson, I. J., & (Eds.). (2004). *Palliative care: the solid facts*. Milan, Italy: World Health Organization.
- Day, J., Higgins, I., & Keatinge, D. (2011). Orientation strategies during delirium: are they helpful? *Journal of Clinical Nursing*, 20, 3285-3294.
- Day, J., Higgins, I., & Koch, T. (2009). The process of practice redesign in delirium care for hospitalised older people: a participatory action research study. *International Journal of Nursing Studies*, 46, 13-22.
- De Jong, J. D., & Clarke, L. E. (2009). What is a good death? Stories from palliative care. *Journal of Palliative Care*, 25(1), 61-67.
- Dean, J. P., & Whyte, W. F. (1958). How do you know if the informant is telling the truth? *Human Organization*, 17, 34-38.
- Dean, R. A., & McClement, S. E. (2002). Palliative care research: methodological and ethical challenges. *International Journal of Palliative Nursing*, 8(8), 376-380.
- Dean, R. A. K., & Gregory, D. M. (2005). More than trivial: strategies for using humor in palliative care. *Cancer Nursing*, 28(4), 292-300.
- Delamont, S. (2004). Ethnography and participant observation. In C. Seale, G. Gobo, J. F. Gubrium & D. Silverman (Eds.), *Qualitative research practice* (pp. 217-229). Thousand Oaks, CA: Sage.
- Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: the discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (pp. 1-42). Thousand Oaks, CA: Sage Publications, Inc.
- Drew, N. (1989). The interviewer's experience as data in phenomenological research. *Western Journal of Nursing Research*, 11(4), 431-439.
- Duarte Enes, S. P. (2003). An exploration of dignity in palliative care. *Palliative Medicine*, 17, 263-269.
- Duppils, G. S., & Wikblad, K. (2007). Patients' experiences of being delirious. *Journal of Clinical Nursing*, 16, 810-818.
- Earle, C. C., Landrum, M. B., Souza, J. M., Neville, B. A., Weeks, J. C., & Ayanian, J. Z. (2008). Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *Journal of Clinical Oncology*, 26(23), 3860-3866.
- Edson, M. (1999). *Wit*. New-York, NY: Faber and Faber, Inc.
- Edvardsson, D., & Street, A. (2007). Sense or no-sense: the nurse as embodied ethnographer. *International Journal of Nursing Practice*, 13, 24-32.
- Edwards, S. D. (2001). *Philosophy of nursing: an introduction*. New-York, NY: Palgrave Macmillan.

- Ellefson, B., & Kim, H. S. (2004). Nurses' construction of clinical situations: a study conducted in an acute-care setting in Norway. *Canadian Journal of Nursing Research, 36*(2), 114-131.
- Ellingson, L. L. (2003). Interdisciplinary health care teamwork in the clinic backstage. *Journal of Applied Communication Research, 31*(2), 93-117.
- Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death. *The Lancet, 351*(Supplement 2), 21-29.
- Emanuel, E. J., Fairclough, D. L., Wolfe, P., & Emanuel, L. L. (2004). Talking with terminally ill patients and their caregivers about death, dying, and bereavement. Is it stressful? Is it helpful? *Archives of Internal Medicine, 164*(18), 1999-2004.
- Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2011). *Writing ethnographic fieldnotes* (2nd ed.). Chicago, IL: University of Chicago Press.
- Engstrom, J., Bruno, E., Holm, B., & Hellzen, O. (2007). Palliative sedation at the end of life: a systematic literature review. *European Journal of Oncology Nursing, 11*, 26-35.
- Evans, M. J., & Hallett, C. E. (2007). Living with dying: a hermeneutic phenomenological study of the work of hospice nurses. *Journal of Clinical Nursing, 16*(4), 742-751.
- Fang, C. K., Chen, H. W., Liu, S. I., Lin, C. J., Tsai, L. Y., & Lai, Y. L. (2008). Prevalence, detection and treatment of delirium in terminal cancer inpatients: a prospective survey. *Japanese Journal of Clinical Oncology, 38*(1), 56-63.
- Fawcett, J., Watson, J., Neuman, B., Walker, P. H., & Fitzpatrick, J. J. (2004[2001]). On nursing theories and evidence. In P. G. Reed, N. B. Crawford Shearer & L. H. Nicoll (Eds.), *Perspectives on nursing theory* (4th ed., pp. 285-292). Philadelphia, PA: Lippincott Williams & Wilkins.
- Fearing, M. A., & Inouye, S. K. (2009). Delirium. *Focus. The Journal of Lifelong Learning in Psychiatry, 7*(1), 53-63.
- Ferrell, B. R., & Coyle, N. (2008). The nature of suffering and the goals of nursing. *Oncology Nursing Forum, 35*(2), 241-247.
- Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., . . . West, P. (2002). *A model to guide hospice palliative care: based on national principles and norms of practice*. Ottawa, ON: Canadian Hospice Palliative Care Association.
- Field, D., & James, N. (1993). Where and how people die. In D. Clark (Ed.), *The future for palliative care: issues of policy and practice* (pp. 6-29). Buckingham, UK: Open University Press.
- Fineout-Overholt, E., Melnyk, B. M., & Schultz, A. (2005). Transforming health care from the inside out: advancing evidence-based practice in the 21st century. *Journal of Professional Nursing, 21*(6), 335-344.
- Finlay, L. (2002). "Outing" the researcher: the provenance, process, and practice of reflexivity. *Qualitative Health Research, 12*(4), 531-545.
- Fins, J. J. (2006). *A palliative ethic of care: clinical wisdom at life's end*. Sudbury, MA: Jones and Bartlett Publishers.
- Flaming, D. (2001a). Using phronesis instead of 'research-based practice' as the guiding light for nursing practice. *Nursing Philosophy, 2*, 251-258.
- Flaming, D. (2001b). Duelling dualisms: a response to Thorne's, 'People and their parts: deconstructing the debates in theorizing nursing's clients'. *Nursing Philosophy, 2*, 263-265.

- Ford-Gilboe, M., & Campbell, J. (1996). The mother-headed single-parent family: a feminist critique of the nursing literature. *Nursing Outlook*, 44, 173-183.
- Frank, A. W. (2004a). Dialogue, dignity, and care. *Journal of Palliative Care*, 20(3), 207-211.
- Frank, A. W. (2004b). After methods, the story: from incongruity to truth in qualitative research. *Qualitative Health Research*, 14, 430-440.
- Freund, P. E. S., & McGuire, M. B. (1999). *Health, illness, and the social body: a critical sociology*. Upper Saddle River, NJ: Prentice Hall.
- Fry, S. T., & Johnstone, M. (2008). *Ethics in nursing practice: a guide to ethical decision making* (3rd ed.). Oxford, UK: Blackwell.
- Gadow, S. (1995). Clinical epistemology: a dialectic of nursing assessment. *Canadian Journal of Nursing Research*, 27(2), 25-34.
- Gadow, S. (1996). Ethical narratives in practice. *Nursing Science Quarterly*, 9, 8-9.
- Gadow, S. (1999). Relational narrative: the postmodern turn in nursing ethics. *Scholarly Inquiry for Nursing Practice*, 13(1), 57-70.
- Gagnon, P. R. (2008). Treatment of delirium in supportive and palliative care. *Current Opinion in Supportive and Palliative Care*, 2(1), 60-66.
- Gallagher, A. (2004). Dignity and respect for dignity - two key health professional values: implications for nursing practice. *Nursing Ethics*, 11(6), 587-599.
- Gallagher, A., Li, S., Wainwright, P., Rees Jones, I., & Lee, D. (2008). Dignity in the care of older people - a review of the theoretical and empirical literature. *BMC Nursing*, 7(11). doi: 10.1186/1472-6955-7-11
- Gaudreau, J. D., Gagnon, P., Harel, F., Tremblay, A., & Roy, M. A. (2005). Fast, systematic, and continuous delirium assessment in hospitalized patients: the nursing delirium screening scale. *Journal of Pain and Symptom Management*, 29(4), 368-375.
- Gawande, A. (2010, August 2). Letting go: what should medicine do when it can't save your life? *The New Yorker*.
- Geer, B. (1964). First days in the field. In P. E. Hammond (Ed.), *Sociologists at work: essays on the craft of social research* (pp. 322-344). New-York, NY: Basic Books.
- Geertz, C. (1973). *The interpretation of cultures: selected essays*. New-York, NY: Basic Books.
- Gelfand, D. E., Raspa, R., Briller, S. H., & Myers Schim, S. (Eds.). (2005). *End-of-life stories: crossing disciplinary boundaries*. New-York, NY: Springer Publishing Company.
- Gillsjo, C., & Schwartz-Barcott, D. (2011). A concept analysis of home and its meaning in the lives of three older adults. *International Journal of Older People Nursing*, 6(1), 4-12.
- Gilmour, J. A. (2006). Hybrid space: constituting the hospital as a home space for patients. *Nursing Inquiry*, 13(1), 16-22.
- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying*. New-York, NY: Aldine Publishing.
- Goffman, E. (1959). *The presentation of self in everyday life*. Garden City, NY: Doubleday.
- Goldsteen, M., Houtepen, R., Proot, I., Abu-Saad, H. H., Spreeuwenberg, C., & Widdershoven, G. (2006). What is a good death? Terminally ill patients dealing

- with normative expectations around death and dying. *Patient Education and Counseling*, 64, 378-386.
- Gottlieb, L. N., & Feeley, N. (2005). *The collaborative partnership approach to care: a delicate balance*. Toronto, ON: Elsevier Canada.
- Gourdji, I., McVey, L., & Purden, M. (2009). A quality end of life from a palliative care patient's perspective. *Journal of Palliative Care*, 25(1), 40-50.
- Granda-Cameron, C., & Houldin, A. (2012). Concept analysis of good death in terminally ill patients. *American Journal of Hospice & Palliative Medicine*, 29, 632-639.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112.
- Gregory, D., & English, J. C. B. (1994). The myth of control: suffering in palliative care. *Journal of Palliative Care*, 10(2), 18-22.
- Grover, S., & Shah, R. (2011). Distress due to delirium experience. *General Hospital Psychiatry*, 33, 637-639.
- Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp. 191-215). Thousand Oaks, CA: Sage.
- Hadders, H. (2011). Negotiating leave-taking events in the palliative medicine unit. *Qualitative Health Research*, 21(2), 223-232.
- Hall, B. A. (2005). *The art of becoming a nurse healer*. Orlando, FL: Bandido Books.
- Hall, P. (2005). Interprofessional teamwork: professional cultures as barriers. *Journal of Interprofessional Care*, 19(Suppl. 1), 188-196.
- Hall, P., McCarney, P., Hamilton, P. D., Robertson, C., & Yates-Fraser, J. (1996). Anne's garden: a journey of the human spirit. *Humane Health Care International*, 12(1), 26-26.
- Hammersley, M., & Atkinson, P. (2007). *Ethnography: principles in practice* (3rd ed.). New-York, NY: Routledge.
- Harris, D. (2007). Delirium in advanced disease. *Postgraduate Medical Journal*, 83, 525-528.
- Hart, B., Sainsbury, P., & Short, S. (1998). Whose dying? A sociological critique of the 'good death'. *Mortality*, 3(1), 65-77.
- Hartrick, G. (1997). Relational capacity: the foundation for interpersonal nursing practice. *Journal of Advanced Nursing*, 26, 523-528.
- Hawthorne, D. L., & Yurkovich, N. J. (2003). Human relationship: the forgotten dynamic in palliative care. *Palliative and Supportive Care*, 1, 261-265.
- Head, B., & Faul, A. (2005). Terminal restlessness as perceived by hospice professionals. *American Journal of Hospice & Palliative Medicine*, 22(4), 277-282.
- Hebert, R. S., Prigerson, H. G., Schulz, R., & Arnold, R. M. (2006). Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. *Journal of Palliative Medicine*, 9(5), 1164-1171.
- Hess, J. D. (2003). Gadow's relational narrative: an elaboration. *Nursing Philosophy*, 4, 137-148.
- Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., . . . Lam, M. (2006). What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal*, 174(5), 627-633.

- Holloway, I., & Todres, L. (2003). The status of method: flexibility, consistency and coherence. *Qualitative Research*, 3(3), 345-357.
- Hopkinson, J. B., Hallett, C. E., & Luker, K. A. (2003). Caring for dying people in hospital. *Journal of Advanced Nursing*, 44(5), 525-533.
- Hshieh, T. T., Fong, T. G., Marcantonio, E. R., & Inouye, S. K. (2008). Cholinergic deficiency hypothesis in delirium: a synthesis of current evidence. *Journal of Gerontology: Medical Sciences*, 63(7), 764-772.
- Hughes, T., Schumacher, M., Jacobs-Lawson, J. M., & Arnold, S. (2008). Confronting death: perceptions of a good death in adults with lung cancer. *American Journal of Hospice & Palliative Medicine*, 25(1), 39-44.
- Hui, D., Con, A., Christie, G., & Hawley, P. H. (2009). Goals of care and end-of-life decision making for hospitalized patients at a Canadian tertiary care cancer center. *Journal of Pain and Symptom Management*, 38(6), 871-881.
- Hunt, M. R., & Carnevale, F. A. (2011). Moral experience: a framework for bioethics research. *Journal of Medical Ethics*, 37, 658-662.
- Hunt, S. M. (1997). The problem of quality of life. *Quality of Life Research*, 6, 205-212.
- Ingallinera, K. (2009). First baby. In D. Witt Sherman (Ed.), *Final moments: nurses' stories about death and dying* (pp. 95-104). New-York, NY: Kaplan Publishing.
- Inouye, S. K. (1994). The dilemma of delirium: clinical and research controversies regarding diagnosis and evaluation of delirium in hospitalized elderly medical patients. *The American Journal of Medicine*, 97, 278-288.
- Inouye, S. K. (2006). Delirium in older persons. *The New England Journal of Medicine*, 354, 1157-1165.
- Inouye, S. K., Foreman, M. D., Mion, L. C., Katz, K. H., & Cooney, L. M. (2001). Nurses' recognition of delirium and its symptoms. *Archives of Internal Medicine*, 161, 2467-2473.
- Jacelon, C. S. (2004). Managing personal integrity: the process of hospitalization for elders. *Journal of Advanced Nursing*, 46(5), 549-557.
- Jacelon, C. S., Connelly, T., Brown, R., Proulx, K., & Vo, T. (2004). A concept analysis of dignity for older adults. *Journal of Advanced Nursing*, 48(1), 76-83.
- James, I., Andershed, B., & Ternestedt, B.-M. (2007). A family's beliefs about cancer, dying, and death in the end of life. *Journal of Family Nursing*, 13(2), 226-252.
- Johnson, D. C., Kassner, C. T., Houser, J., & Kutner, J. S. (2005). Barriers to effective symptom management in hospice. *Journal of Pain and Symptom Management*, 29(1), 69-79.
- Johnson, M. (1999). Observations on positivism and pseudoscience in qualitative nursing research. *Journal of Advanced Nursing*, 30(1), 67-73.
- Johnson, N., Cook, D., Giacomini, M., & Willms, D. (2000). Towards a "good" death: end-of-life narratives constructed in an intensive care unit. *Culture, Medicine and Psychiatry*, 24, 275-295.
- Johnston, B., & Smith, L. N. (2006). Nurses' and patients' perceptions of expert palliative nursing care. *Journal of Advanced Nursing*, 54(6), 700-709.
- Josselson, R. (1996). *The space between us: exploring the dimensions of human relationships*. Thousand Oaks, CA: Sage Publications, Inc.
- Kahn, D. L., & Steeves, R. H. (1986). The experience of suffering: conceptual clarification and theoretical definition. *Journal of Advanced Nursing*, 11, 623-631.

- Kaufman, S. R. (1998). Intensive care, old age, and the problem of death in America. *The Gerontologist*, 38(6), 715-725.
- Kayser-Jones, J. (2002). The experience of dying: an ethnographic nursing home study. *The Gerontologist*, 42(Special Issue III), 11-19.
- Kearney, M. (1992). Palliative medicine - just another specialty? *Palliative Medicine*, 6, 39-46.
- Kehl, K. A. (2006). Moving toward peace: an analysis of the concept of a good death. *American Journal of Hospice & Palliative Medicine*, 23(4), 277-286.
- Kellehear, A. (2009). On dying and human suffering. *Palliative Medicine*, 23(5), 388-397.
- Kessler, D. (2007). *The needs of the dying: tenth anniversary edition*. New-York, NY: HarperCollins.
- Kessler, D. (2010). *Visions, trips, and crowded rooms: who and what you see before you die*. Carlsbad, CA: Hay House USA.
- Kjorven, M. C. (2009). *An exploration of the discursive practices that shape and discipline nurses' response to postoperative delirium*. (Unpublished Master's Thesis), The University of British Columbia.
- Kleinman, A. (1992). Local worlds of suffering: an interpersonal focus for ethnographies of illness experience. *Qualitative Health Research*, 2(2), 127-134.
- Kleinman, A. (1999). Moral experience and ethical reflection: can ethnography reconcile them? A quandary for "The new bioethics". *Daedalus*, 128(4), 69-97.
- Koch, T. (2006[1994]). Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing*, 53(1), 91-103.
- Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: the case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882-890.
- Koenig, B. A., Back, A. L., & Crawley, L. M. (2003). Qualitative methods in end-of-life research: recommendations to enhance the protection of human subjects. *Journal of Pain and Symptom Management*, 25(4), S43-S52.
- Kress, J. P., & Hall, J. B. (2004). Delirium and sedation. *Critical Care Clinics*, 20, 419-433.
- Kring, D. L. (2006). An exploration of the good death. *Advances in Nursing Science*, 29(3), E12-E24.
- Krisman-Scott, M. A., & McCorkle, R. (2002). The tapestry of hospice. *Holistic Nursing Practice*, 16(2), 32-39.
- Larkin, P. (2010). Listening to the still small voice: the role of palliative care nurses in addressing psychosocial issues at end of life. *Progress in Palliative Care*, 18(6), 335-340.
- Larkin, P. J., Dierckx de Casterle, B., & Schotsmans, P. (2007). Towards a conceptual evaluation of transience in relation to palliative care. *Journal of Advanced Nursing*, 59(1), 86-96.
- Lawlor, P., & Bruera, E. (2002). Delirium in patients with advanced cancer. *Hematology/Oncology Clinics of North America*, 16, 701-714.
- Lawlor, P., Gagnon, P., Mancini, I., Pereira, J., Suarez-Almazor, M., & Bruera, E. (2000). Occurrence, causes, and outcome of delirium in patients with advanced cancer: a prospective study. *Archives of Internal Medicine*, 160, 786-794.
- Lawton, J. (1998). Contemporary hospice care: the sequestration of the unbounded body and 'dirty dying'. *Sociology of Health & Illness*, 20(2), 121-143.

- Lawton, J. (2000). *The dying process: patients' experiences of palliative care*. Abingdon, UK: Routledge.
- Lee, N. P., & Washington, G. (2008). Management of common symptoms at end of life in acute care settings. *The Journal for Nurse Practitioners*, 4(8), 610-615.
- Lee, S., & Kristjanson, L. (2003). Human research ethics committees: issues in palliative care research. *International Journal of Palliative Nursing*, 9(1), 13-18.
- LeGrand, S. B. (2012). Delirium in palliative medicine: a review. *Journal of Pain and Symptom Management*, 44, 583-594.
- Leonard, M., Agar, M., Mason, C., & Lawlor, P. (2008). Delirium issues in palliative care settings. *Journal of Psychosomatic Research*, 65, 289-298.
- Leonard, M., Spiller, J., Keen, J., MacLulich, A., Kamholtz, B., & Meagher, D. (2009). Symptoms of depression and delirium assessed serially in palliative-care inpatients. *Psychosomatics*, 50, 506-514.
- Leplege, A., & Hunt, S. (1997). The problem of quality of life in medicine. *Journal of the American Medical Association*, 278, 47-50.
- Levetown, M. (2006). Pediatric care: transitioning goals of care in the emergency department, intensive care unit, and in between. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of Palliative Nursing* (pp. 925-943). New-York, NY: Oxford University Press.
- Levine, M. E. (1977). Nursing ethics and the ethical nurse. *American Journal of Nursing*, 77(5), 845-849.
- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lipowski, Z. J. (1982). Differentiating delirium from dementia in the elderly. *Clinical Gerontologist*, 1(1), 3-10.
- Lowe, L. M., & Cutcliffe, J. R. (2005). A concept analysis of comfort. In J. R. Cutcliffe & H. P. McKenna (Eds.), *The essential concepts of nursing* (pp. 51-64). London, UK: Elsevier.
- Lowey, S. E. (2008). Letting go before a death: a concept analysis. *Journal of Advanced Nursing*, 63(2), 208-215.
- Lynch, M., Dahlin, C., Hultman, T., & Coakley, E. E. (2011). Palliative care nursing: defining the discipline? *Journal of Hospice and Palliative Nursing*, 13(2), 106-111.
- Lyness, J. M. (2004). End-of-life care: issues relevant to the geriatric psychiatrist. *American Journal of Geriatric Psychiatry*, 12(5), 457-472.
- Macdonald, M. (2007). Origins of difficulty in the nurse-patient encounter. *Nursing Ethics*, 14, 510-521.
- Macdonald, M. E., & Carnevale, F. A. (2008). Qualitative health research and the IRB: answering the "so what?" with qualitative inquiry. *Journal of Academic Ethics*, 6, 1-5.
- Mackenzie, A. E. (1994). Evaluating ethnography: considerations for analysis. *Journal of Advanced Nursing*, 19, 774-781.
- Macleod, A. D. (2006a). Delirium: the clinical concept. *Palliative and Supportive Care*, 4, 305-312.
- Macleod, A. D. (2006b). The management of terminal delirium. *Indian Journal of Palliative Care*, 12(1), 22-28.
- Macleod, A. D. (2009). Lightening up before death. *Palliative and Supportive Care*, 7, 513-516.

- Macleod, A. D. (2011). *The psychiatry of palliative medicine: the dying mind* (2nd ed.). New-York, NY: Radcliffe Publishing.
- Maggs-Rapport, F. (2000). Combining methodological approaches in research: ethnography and interpretive phenomenology. *Journal of Advanced Nursing*, 31(1), 219-225.
- Mak, J. M. H., & Clinton, M. (1999). Promoting a good death: an agenda for outcomes research - a review of the literature. *Nursing Ethics*, 6(2), 97-106.
- Maluso-Bolton, T. (2000). Terminal agitation. *Journal of Hospice and Palliative Nursing*, 2(1), 9-20.
- Marantz Henig, R. (2005, August 7). Will we ever arrive at the good death? *The New York Times Magazine*, 13.
- Marchington, K. L., Carrier, L., & Lawlor, P. G. (2012). Delirium masquerading as depression. *Palliative and Supportive Care*, 10, 59-62.
- Martins Pereira, S., Fonseca, A. M., & Carvalho, A. S. (2011). Burnout in palliative care: a systematic review. *Nursing Ethics*, 18(3), 317-326.
- Maxwell, J. A. (2005). *Qualitative research design - an interactive approach* (2nd ed.). Thousand Oaks, CA: Sage.
- McCarthy, M. C. (2003). Detecting acute confusion in older adults: comparing clinical reasoning of nurses working in acute, long-term, and community health care environments. *Research in Nursing & Health*, 26(3), 203-212.
- McClement, S. E., Chochinov, H. M., Hack, T. F., Kristjanson, L. J., & Harlos, M. (2004). Dignity conserving care: application of research findings to practice. *International Journal of Palliative Nursing*, 10(4), 173-179.
- McCurran, C., & Cronin, S. N. (2003). Delirium: elders tell their stories and guide nursing practice. *Medsurg Nursing*, 12(5), 318-323.
- McInerney, F. (2007). Death and the body beautiful: aesthetics and embodiment in press portrayals of requested death in Australia on the edge of the 21st century. *Health Sociology Review*, 16, 384-396.
- McIntosh, E., & Zerwekh, J. (2006). Hospice and palliative care. In J. Zerwekh (Ed.), *Nursing care at the end of life: palliative care for patients and families* (pp. 21-39). Philadelphia, PA: F.A. Davis Company.
- McNamara, B. (2001). *Fragile lives: death, dying, and care*. Buckingham, UK: Open University Press.
- McNamara, B. (2004). Good enough death: autonomy and choice in Australian palliative care. *Social Science & Medicine*, 58(5), 929-938.
- McNamara, B., & Rosenwax, L. (2007). The mismanagement of dying. *Health Sociology Review*, 16, 373-383.
- McNamara, B., Waddell, C., & Colvin, M. (1995). Threats to the good death: the cultural context of stress and coping among hospice nurses. *Sociology of Health & Illness*, 17(2), 222-244.
- Meagher, D. J. (2001). Delirium: optimizing management. *British Medical Journal*, 322, 144-149.
- Meghani, S. H. (2004). A concept analysis of palliative care in the United States. *Journal of Advanced Nursing*, 46(2), 152-161.

- Mehta, A., & Chan, L. S. (2008). Understanding the concept of "total pain". A prerequisite for pain control. *Journal of Hospice and Palliative Nursing*, 10(1), 26-32.
- Meiers, S. J., & Brauer, D. J. (2008). Existential caring in the family health experience: a proposed conceptualization. *Scandinavian Journal of Caring Sciences*, 22, 110-117.
- Mills, J., Bonner, A., & Francis, K. (2006). Adopting a constructivist approach to grounded theory: implications for research design. *International Journal of Nursing Practice*, 12, 8-13.
- Mok, E., & Chiu, P. C. (2004). Nurse-patient relationships in palliative care. *Journal of Advanced Nursing*, 48(5), 475-483.
- Monti, E. J., & Tingen, M. S. (1999). Multiple paradigms of nursing science. *Advances in Nursing Science*, 21(4), 64-80.
- Morita, T., Akechi, T., Ikenaga, M., Inoue, S., Kohara, H., Matsubara, T., . . . Uchitomi, Y. (2007). Terminal delirium: recommendations from bereaved families' experiences. *Journal of Pain and Symptom Management*, 34(6), 579-589.
- Morita, T., Tei, Y., Tsunoda, J., Inoue, S., & Chihara, S. (2001). Underlying pathologies and their associations with clinical features in terminal delirium of cancer patients. *Journal of Pain and Symptom Management*, 22(6), 997-1006.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), Article 2. Retrieved from http://www.ualberta.ca/~iiqm/backissues/1_2Final/pdf/morseetal.pdf
- Mount, B. (1993). Whole person care: beyond psychosocial and physical needs. *American Journal of Hospice & Palliative Care*, 10, 28-37.
- Mount, B. M. (2003). Existential suffering and the determinants of healing. *European Journal of Palliative Care*, 10(2 Supplement), 40-42.
- Mount, B. M., Boston, P. H., & Cohen, S. R. (2007). Healing connections: on moving from suffering to a sense of well-being. *Journal of Pain and Symptom Management*, 33(4), 372-388.
- Moyer, D. D. (2011). Terminal delirium in geriatric patients with cancer at end of life. *American Journal of Hospice & Palliative Medicine*, 28(1), 44-51.
- Mueke, M. A. (1994). On the evaluation of ethnographies. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 187-209). Newbury Park, CA: Sage Publications.
- Mulhall, A. (2003). In the field: notes on observation in qualitative research. *Journal of Advanced Nursing*, 41(3), 306-313.
- Munhall, P. L. (1993). 'Unknowing': toward another pattern of knowing in nursing. *Nursing Outlook*, 41(3), 125-128.
- Murray, M. A., Miller, T., Fiset, V., O'Connor, A., & Jacobsen, M. J. (2004). Decision support: helping patients and families to find a balance at the end of life. *International Journal of Palliative Nursing*, 10(6), 270-277.
- Namba, M., Morita, T., Imura, C., Kiyohara, E., Ishikawa, S., & Hirai, K. (2007). Terminal delirium: families' experience. *Palliative Medicine*, 21(7), 587-594.
- National Comprehensive Cancer Network. (2012). Clinical practice guidelines in oncology: palliative care (Version 2.2012 ed.). Fort Washington, PA.

- Nelson, G. (2000). Maintaining the integrity of personhood in palliative care. *Scottish Journal of Healthcare Chaplaincy*, 3(2), 34-39.
- Neville, S. (2006). Delirium and older people: repositioning nursing care. *International Journal of Older People Nursing*, 1(2), 113-120.
- Neville, S. (2008). Older people with delirium: worthless and childlike. *International Journal of Nursing Practice*, 14(6), 463-469.
- Newman, M. A., Sime, A. M., & Corcoran-Perry, S. A. (2004[1991]). The focus of the discipline of nursing. In P. G. Reed, N. C. Shearer & L. H. Nicoll (Eds.), *Perspectives on nursing theory* (4th ed., pp. 315-320). Philadelphia, PA: Lippincott Williams & Wilkins.
- Nolan, M. T., & Mock, V. (2004). A conceptual framework for end-of-life care: a reconsideration of factors influencing the integrity of the human person. *Journal of Professional Nursing*, 20(6), 351-360.
- Nordenfelt, L. (2003). Dignity of the elderly: an introduction. *Medicine, Health Care and Philosophy*, 6, 99-101.
- Nordenfelt, L. (2004). The varieties of dignity. *Health Care Analysis*, 12(2), 69-81.
- Northcott, H. C., & Wilson, D. M. (2001). *Dying & Death in Canada*. Aurora, ON: Garamond Press.
- Norton, S. A., & Bowers, B. J. (2001). Working toward consensus: providers' strategies to shift patients from curative to palliative treatment choices. *Research in Nursing & Health*, 24, 258-269.
- O'Connor, M., Davis, M. P., & Abernethy, A. (2010). Language, discourse, and meaning in palliative medicine. *Progress in Palliative Care*, 18(2), 66-71.
- O'Malley, G., Leonard, M., Meagher, D., & O'Keeffe, S. T. (2008). The delirium experience: a review. *Journal of Psychosomatic Research*, 65, 223-228.
- O'Reilly, M., & Parker, N. (in press). 'Unsatisfactory saturation': a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, doi: 10.1177/1468794112446106
- Oakley, A. (1998). Interviewing women; a contradiction in terms. In J. Kourany (Ed.), *Scientific knowledge: basic issues in the philosophy of science* (2nd ed., pp. 117-134). Toronto, ON: Wadsworth.
- Oberle, K., & Raffin Bouchal, S. (2009). *Ethics in Canadian nursing practice*. Toronto, ON: Pearson Canada.
- Oliffe, J. (2005). Why not ethnography? *Urologic Nursing*, 25(5), 395-399.
- Paley, J. (2002). The Cartesian melodrama in nursing. *Nursing Philosophy*, 3, 189-192.
- Pastrana, T., Junger, S., Ostgathe, C., Elsner, F., & Radbruch, L. (2008). A matter of definition - key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine*, 22, 222-232.
- Payne, S. A., Langley-Evans, A., & Hillier, R. (1996). Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. *Palliative Medicine*, 10, 307-312.
- Perry, B. (1998). *Moments in time: images of exemplary nursing care*. Ottawa, ON: Canadian Nurses Association.
- Perry, B. (2009). Achieving professional fulfillment as a palliative care nurse. *Journal of Hospice and Palliative Nursing*, 11(2), 109-118.

- Perry, B. A. (1994). *A description of exceptionally competent nursing practice*. (Unpublished PhD thesis), The University of Alberta, Edmonton, AB.
- Playle, J. F. (1995). Humanism and positivism in nursing: contradictions and conflicts. *Journal of Advanced Nursing*, 22, 979-984.
- Polifroni, E. C. (1999). Truth: an exploration. In E. C. Polifroni & M. Welch (Eds.), *Perspectives on philosophy of science in nursing: an historical and contemporary anthology* (pp. 55-60). Philadelphia, PA: Lippincott Williams & Wilkins.
- Polit, D. F., & Beck, C. T. (2004). *Nursing research: principles and methods* (7th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Poole, J., & Mott, S. (2003). Agitated older patients: nurses' perceptions and reality. *International Journal of Nursing Practice*, 9, 306-312.
- Proulx, K., & Jacelon, C. (2004). Dying with dignity: the good patient versus the good death. *American Journal of Hospice & Palliative Medicine*, 21(2), 116-120.
- Pullman, D. (2002). Human dignity and the ethics and aesthetics of pain and suffering. *Theoretical Medicine and Bioethics*, 23, 75-94.
- Pullman, D. (2004). Death, dignity, and moral nonsense. *Journal of Palliative Care*, 20(3), 171-178.
- Quill, T. E., Arnold, R., & Back, A. L. (2009). Discussing treatment preferences with patients who want "everything". *Annals of Internal Medicine*, 151, 345-349.
- Ramsay, P. (2011). Health-related quality of life: implications for critical care interventional studies and why we need to collaborate with patients. *Current Opinion in Critical Care*, 17, 510-514.
- Rao, S., Ferris, F. D., & Irwin, S. A. (2011). Ease of screening for depression and delirium in patients enrolled in inpatient hospice care. *Journal of Palliative Medicine*, 14(3), 275-279.
- Rasmussen, B. H., Sandman, P., & Norberg, A. (1997). Stories of being a hospice nurse: a journey towards finding one's footing. *Cancer Nursing*, 20(5), 330-341.
- Reed, P. G. (2008). Practitioner as theorist: a reprise. *Nursing Science Quarterly*, 21(4), 315-321.
- Reed, P. G., & Crawford Shearer, N. B. (Eds.). (2011). *Nursing knowledge and theory innovation: advancing the science of practice*. New-York, NY: Springer Publishing Company.
- Reed, P. G., & Lawrence, L. A. (2008). A paradigm for the production of practice-based knowledge. *Journal of Nursing Management*, 16, 422-432.
- Registered Nurses' Association of Ontario. (2011). Clinical best practice guidelines: end-of-life care during the last days and hours. Toronto, ON.
- Reinharz, S. (1992). *Feminist methods in social research*. New-York, NY: Oxford University Press.
- Rhynas, S. J. (2010). *'Forgotten shopping, lost keys and hearts which forget to beat': an exploration of nurses' conceptualisation of dementia*. (Unpublished PhD Thesis), University of Edinburgh, Edinburgh, UK.
- Rice, K. L., Bennett, M., Gomez, M., Theall, K. P., Knight, M., & Foreman, M. D. (2011). Nurses' recognition of delirium in the hospitalized older adult. *Clinical Nurse Specialist*, 25(6), 299-311.
- Robertson, M. H., & Boyle, J. S. (1984). Ethnography: contributions to nursing research. *Journal of Advanced Nursing*, 9(1), 43-49.

- Robinson Wolf, Z. (1988). *Nurses' work, the sacred and the profane*. Philadelphia, PA: University of Pennsylvania Press.
- Robinson-Wolf, Z. (2007). Ethnography: the method. In P. L. Munhall (Ed.), *Nursing research: a qualitative perspective* (4th ed., pp. 293-330). Sudbury, MA: Jones and Bartlett Publishers.
- Rodgers, B. L. (2005). *Developing nursing knowledge: philosophical traditions and influences*. Philadelphia, PA: Lippincott Williams & Wilkins.
- Rodgers, B. L., & Cowles, K. V. (1997). A conceptual foundation for human suffering in nursing care and research. *Journal of Advanced Nursing*, 25, 1048-1053.
- Rolfe, G. (2006a). Nursing praxis and the science of the unique. *Nursing Science Quarterly*, 19(1), 39-43.
- Rolfe, G. (2006b). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, 53(3), 304-310.
- Rolfe, G., & Gardner, L. (2005). Towards a nursing science of the unique: evidence, reflexivity and the study of persons. *Journal of Research in Nursing*, 10, 297-310.
- Roper, J. M., & Shapira, J. (2000). *Ethnography in nursing research*. Thousand Oaks, CA: Sage Publications, Inc.
- Roth, A. J., & Breitbart, W. (1996). Psychiatric emergencies in terminally ill cancer patients. *Hematology/Oncology Clinics of North America*, 10(1), 235-259.
- Roy, D. J. (2012). Untruths about palliative care. *Journal of Palliative Care*, 28(1), 3-4.
- Ruland, C. M., & Moore, S. M. (1998). Theory construction based on standards of care: a proposed theory of the peaceful end of life. *Nursing Outlook*, 46(4), 169-175.
- Russell, C. K., & Gregory, D. M. (2003). Evaluation of qualitative research studies. *Evidence Based Nursing*, 6, 36-40.
- Sadler, K. (2012). Palliative sedation to alleviate existential suffering at end-of-life: insight into a controversial practice. *Canadian Oncology Nursing Journal*, 22(3), 195-199.
- Sakalys, J. A. (2003). Restoring the patient's voice: the therapeutics of illness narratives. *Journal of Holistic Nursing*, 21(3), 228-241.
- Sandelowski, M. (2003). Taking things seriously: studying the material culture of nursing. In J. Latimer (Ed.), *Advanced qualitative research for nursing* (pp. 185-210). Oxford, UK: Blackwell Science.
- Sandman, L. (2005). Should people die a natural death? *Health Care Analysis*, 13(4), 275-287.
- Saunders, C. (1965). The last stages of life. *American Journal of Nursing*, 65(3), 70-75.
- Saunders, C. (1988). Spiritual pain. *Journal of Palliative Care*, 4, 29-32.
- Saunders, C. (1996). Hospice. *Mortality*, 1(3), 317-322.
- Saunders, C. (2000). The evolution of palliative care. *Patient Education and Counseling*, 41, 7-13.
- Saunders, C. (2006). Foreward. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of Palliative Nursing* (2nd ed., pp. v-vi). New-York, NY: Oxford University Press.
- Saunders, C., & Baines, M. (1983). *Living with dying: the management of terminal disease*. Oxford, UK: Oxford University Press.
- Savage, J. (2006). Ethnographic evidence: the value of applied ethnography in health care. *Journal of Research in Nursing*, 11(5), 383-393.

- Schofield, I., Tolson, D., & Fleming, V. (2012). How nurses understand and care for older people with delirium in the acute hospital: a critical discourse analysis. *Nursing Inquiry*, 19(2), 165-176.
- Schott, T. (2009). *Nursing practice: what about not knowing?* (Unpublished Master's Thesis), University of Victoria.
- Schultz, D. S., & Carnevale, F. A. (1996). Engagement and suffering in responsible caregiving: on overcoming maleficence in health care. *Theoretical Medicine and Bioethics*, 17(3), 189-207.
- Scott, H. (2005). Nurses should become more skilled in palliative care. *British Journal of Nursing*, 14(12), 631.
- Scott, P. A. (2006). Perceiving the moral dimension of practice: insights from Murdoch, Vetlesen, and Aristotle. *Nursing Philosophy*, 7, 137-145.
- Seale, C., & van der Geest, S. (2004). Good and bad death: Introduction. *Social Science & Medicine*, 58, 883-885.
- Seamark, D. A., Gilbert, J., Lawrence, C. J., & Williams, S. (2000). Are postbereavement research interviews distressing to carers? Lessons learned from palliative care research. *Palliative Medicine*, 14(1), 55-56.
- Seymour, J. (2000). Negotiating natural death in intensive care. *Social Science & Medicine*, 51, 1241-1252.
- Seymour, J. (2001). *Critical moments - death and dying in intensive care*. Philadelphia, PA: Open University Press.
- Seymour, J., & Clark, D. (1998). Phenomenological approaches to palliative care research. *Palliative Medicine*, 12, 127-131.
- Seymour, J., Clark, D., & Winslow, M. (2005). Pain and palliative care: the emergence of new specialties. *Journal of Pain and Symptom Management*, 29(1), 2-13.
- Seymour, J., Ingleton, C., Payne, S., & Beddow, V. (2003). Specialist palliative care: patients' experiences. *Journal of Advanced Nursing*, 44(1), 24-33.
- Seymour, J., Payne, S., Reid, D., Sargeant, A., Skilbeck, J., & Smith, P. (2005). Ethical and methodological issues in palliative care studies: the experiences of a research group. *Journal of Research in Nursing*, 10(2), 169-188.
- Shapin, S. (1998). Pump and circumstance: Robert Boyle's literary technology. In J. Kourany (Ed.), *Scientific knowledge: basic issues in the philosophy of science* (2nd ed., pp. 100-116). Toronto, ON: Wadsworth.
- Shirley, J. L. (2007). Limits of autonomy in nursing's moral discourse. *Advances in Nursing Science*, 30(1), 14-25.
- Shuster, J. L. (1998). Delirium, confusion, and agitation at the end of life. *Journal of Palliative Medicine*, 1(2), 177-186.
- Sigsworth, J. (1995). Feminist research: its relevance to nursing. *Journal of Advanced Nursing*, 22, 896-899.
- Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: patients' perspectives. *Journal of the American Medical Association*, 281, 163-168.
- Sjolander, C., Hedberg, B., & Ahlstrom, G. (2011). Striving to be prepared for the painful: management strategies following a family member's diagnosis of advanced cancer. *BMC Nursing*, 10(18). doi: 10.1186/1472-6955-10-18
- Ski, C., & O'Connell, B. (2006). Mismanagement of delirium places patients at risk. *Australian Journal of Advanced Nursing*, 23(3).

- Skilbeck, J., & Payne, S. (2003). Emotional support and the role of Clinical Nurse Specialists in palliative care. *Journal of Advanced Nursing*, 43(5), 521-530.
- Smith, J., & Adcock, L. (2011). The recognition of delirium in hospice inpatient units. *Palliative Medicine*, 26(3), 283-285.
- Smith, L. S. (2002). How to chart by exception. *Nursing*, 32(9), 30.
- Smith, R. (2000). A good death: an important aim for health services and for us all. *British Medical Journal*, 320, 129-130.
- Spiller, J. A., & Keen, J. C. (2006). Hypoactive delirium: assessing the extent of the problem for inpatient specialist palliative care. *Palliative Medicine*, 20(1), 17-23.
- Spradley, J. P. (1980). *Participant observation*. New-York, NY: Holt, Rinehart, and Winston.
- Stagno, D., Gibson, C., & Breitbart, W. (2004). The delirium subtypes: a review of prevalence, phenomenology, pathophysiology, and treatment response. *Palliative and Supportive Care*, 2, 171-179.
- Stajduhar, K. I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care*, 19(1), 27-35.
- Stajduhar, K. I., Nickel, D. D., Martin, W. L., & Funk, L. (2008). Situated/being situated: Client and co-worker roles of family caregivers in hospice palliative care. *Social Science & Medicine*, 67, 1789-1797.
- Stanley, P. (2004). The patient's voice: a cry in solitude or a call for community. *Literature and Medicine*, 23(2), 346-363.
- Stayt, L. C. (2007). Nurses' experiences of caring for families with relatives in intensive care units. *Journal of Advanced Nursing*, 57(6), 623-630.
- Steeves, R., & Kahn, D. (2006). Understanding a good death: James's story. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of Palliative Nursing* (pp. 1209-1215). New-York, NY: Oxford University Press.
- Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: observations of patients, families, and providers. *Annals of Internal Medicine*, 132(10), 825-832.
- Steis, M. R., & Fick, D. M. (2008). Are nurses recognizing delirium? A systematic review. *Journal of Gerontological Nursing*, 34(9), 40-48.
- Stenwall, E., Sandberg, J., Eriksdotter Jonhagen, M., & Fagerberg, I. (2008). Relatives' experiences of encountering the older person with acute confusional state: experiencing unfamiliarity in a familiar person. *International Journal of Older People Nursing*, 3(4), 243-251.
- Street, A. F., & Kissane, D. W. (2001). Constructions of dignity in end-of-life care. *Journal of Palliative Care*, 17(2), 93-101.
- Streubert Speziale, H. J. (2003). The conduct of qualitative research: common essential elements. In H. J. Streubert Speziale & D. Rinaldi Carpenter (Eds.), *Qualitative research in nursing: advancing the humanistic imperative* (3rd ed., pp. 15-26). Philadelphia, PA: Lippincott Williams & Wilkins.
- SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Journal of the American Medical Association*, 274, 1591-1598.

- Tanner, C. A. (2006). Thinking like a nurse: a research-based model of clinical judgment in nursing. *Journal of Nursing Education*, 45(6), 204-211.
- Tanner, C. A., Benner, P., Chesla, C., & Gordon, D. R. (1993). The phenomenology of knowing the patient. *Image: Journal of Nursing Scholarship*, 25(4), 273-280.
- Tarlier, D. S. (2004). Beyond caring: the moral and ethical bases of responsive nurse-patient relationships. *Nursing Philosophy*, 5, 230-241.
- Taylor, C. (1985). *Philosophy and the human sciences: philosophical papers* (Vol. 2). New-York, NY: Cambridge University Press.
- Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association*, 291(1), 88-93.
- Ternstedt, B.-M., Andershed, B., Eriksson, M., & Johansson, I. (2002). A good death: development of a nursing model of care. *Journal of Hospice and Palliative Nursing*, 4(3), 153-160.
- Thompson, G. N., McClement, S. E., & Daeninck, P. J. (2006). "Changing lanes": facilitating the transition from curative to palliative care. *Journal of Palliative Care*, 22(2), 91-98.
- Thorne, S. E. (2001). People and their parts: deconstructing the debates in theorizing nursing's clients. *Nursing Philosophy*, 2, 259-262.
- Thorne, S. E., Henderson, A. D., McPherson, G. I., & Pesut, B. K. (2004). The problematic allure of the binary in nursing theoretical discourse. *Nursing Philosophy*, 5, 208-215.
- Thorne, S. E., Kuo, M., Armstrong, E. A., McPherson, G., Harris, S. R., & Hislop, T. G. (2005). 'Being known': patients' perspectives of the dynamics of human connection in cancer care. *Psycho-Oncology*, 14, 887-898.
- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, 48(4), 388-396.
- Tracy, S. J. (2010). Qualitative quality: eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837-851.
- Trzepacz, P., Breitbart, W., Franklin, J., Levenson, J., Martini, D. R., & Wang, P. (1999). *Practice guideline for the treatment of patients with delirium*: American Psychiatric Association.
- Turner, L. (2002). Medical facilities as moral worlds. *Medical Humanities*, 28(1), 19-22.
- Twycross, R. (2007). Patient care: past, present, and future. *Omega - Journal of Death and Dying*, 56(1), 7-19.
- Valentine, C. (2008). *Bereavement narratives: continuing bonds in the twenty-first century*. Abingdon, UK: Routledge.
- Vig, E. K., & Pearlman, R. A. (2004). Good and bad dying from the perspective of terminally ill men. *Archives of Internal Medicine*, 164, 977-981.
- Volker, D. L., & Limerick, M. (2007). What constitutes a dignified death? The voice of oncology advanced practice nurses. *Clinical Nurse Specialist*, 21(5), 241-247.
- Wainwright, P., & Gallagher, A. (2008). On different types of dignity in nursing care: a critique of Nordenfelt. *Nursing Philosophy*, 9(1), 46-54.
- Walters, G. (2004). Is there such a thing as a good death? *Palliative Medicine*, 18, 404-408.

- Waskul, D. D., & van der Riet, P. (2002). The abject embodiment of cancer patients: dignity, selfhood, and the grotesque body. *Symbolic Interaction*, 25(4), 487-513.
- Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing*, 53(4), 459-469.
- Wentlandt, K., & Zimmermann, C. (2012). Aggressive treatment and palliative care at the end of life. In J. Cohen & L. Deliens (Eds.), *A public health perspective on end of life care* (pp. 73-85). Oxford, UK: Oxford University Press.
- Whelton, B. J. B. (2008). Human nature: a foundation for palliative care. *Nursing Philosophy*, 9, 77-88.
- White, S., & Bayer, A. (2007). Delirium - a clinical overview. *Reviews in Clinical Gerontology*, 17, 45-62.
- Wilde, M. H. (1999). Why embodiment now? *Advances in Nursing Science*, 22(2), 25-38.
- Williams, A. M., Crooks, V. A., Whitfield, K., Kelley, M. L., Richards, J. L., DeMiglio, L., & Dykeman, S. (2010). Tracking the evolution of hospice palliative care in Canada: a comparative case study analysis of seven provinces. *BMC Health Services Research*, 10(147). doi: 10.1186/1472-6963-10-147
- Williams, M. A. (1991). Delirium / acute confusional states: evaluation devices in nursing. *International Psychogeriatrics*, 3(2), 301-308.
- Willis, D. G., Grace, P. J., & Roy, C. (2008). A central unifying focus for the discipline: facilitating humanization, meaning, choice, quality of life, and healing in living and dying. *Advances in Nursing Science*, 31(1), E28-E40.
- Wilson, D. M., Fillion, L., Thomas, R., Justice, C., Bhardwaj, P. P., & Veillette, A. (2009). The "good" rural death: a report of an ethnographic study in Alberta, Canada. *Journal of Palliative Care*, 25(1), 21-29.
- Wilson, D. M., Low, G., Thurston, A., Lichlyter, B., Kinch, J., Fahey, F., & Clarkes, M. A. (2010). Nursing practices to detect acute delirium, safeguard patients experiencing acute delirium, and help reduce or eliminate acute delirium. *Global Journal of Health Science*, 2(1), 81-88.
- Wilson, D. M., Truman, C. D., Thomas, R., Fainsinger, R., Kovacs-Burns, K., Froggatt, K. A., & Justice, C. (2009). The rapidly changing location of death in Canada, 1994-2004. *Social Science & Medicine*, 68(10), 1752-1758.
- Wilson, S. A., Coenen, A., & Doorenbos, A. (2006). Dignified dying as a nursing phenomenon in the United States. *Journal of Hospice and Palliative Nursing*, 8(1), 34-41.
- Wong, C. L., Holroyd-Leduc, J., Simel, D. L., & Straus, S. E. (2010). Does this patient have delirium? Value of bedside instruments. *Journal of the American Medical Association*, 304(7), 779-786.
- Wood, S. (2008). Anatomy and physiology of pain. Retrieved July 24, 2012, from <http://www.nursingtimes.net/nursing-practice/1860931.article>
- Woods, S. (2004). Is terminal sedation compatible with good nursing care at the end of life? *International Journal of Palliative Nursing*, 10(5), 244-247.
- Woods, S. (2007). *Death's dominion: ethics at the end of life*. New-York, NY: Open University Press.
- Wright, D., & Brajtman, S. (2011). Relational and embodied knowing: nursing ethics within the interprofessional team. *Nursing Ethics*, 18(1), 20-30.

- Wright, D., Brajtman, S., & Bitzas, V. (2009). Human relationships at the end of life: an ethical ontology for practice. *Journal of Hospice and Palliative Nursing*, 11(4), 219-227.
- Wright, D., & Pugnaire-Gros, C. (2010). Let's talk about sex: promoting staff dialogue on a mental health nursing unit. *Journal for Nurses in Staff Development*, 26(6), 250-255.
- Wright, D., & Pugnaire-Gros, C. (2012). Theory inspired practice for end-of-life cancer care: an exploration of the McGill Model of Nursing. *Canadian Oncology Nursing Journal*, 22(3), 175-181.
- Wright, D. J. (2002). Researching the qualities of hospice nurses. *Journal of Hospice and Palliative Nursing*, 4(4), 210-216.
- Wu, H. L., & Volker, D. L. (2009). Living with death and dying: the experience of Taiwanese hospice nurses. *Oncology Nursing Forum*, 36(5), 578-584.
- Wu, H. L., & Volker, D. L. (2012). Humanistic nursing theory: application to hospice and palliative care. *Journal of Advanced Nursing*, 68(2), 471-479.
- Zimmermann, C. (2012). Acceptance of dying: a discourse analysis of palliative care literature. *Social Science & Medicine*, 75, 217-224.
- Zimmermann, C., & Wennberg, R. (2006). Integrating palliative care: a postmodern perspective. *American Journal of Hospice & Palliative Medicine*, 23(4), 255-258.

Appendix A: Sample Interview Questions

What is this place (hospice) all about?

What does a good death mean to you?

Are most of the deaths here good deaths? How do you know?

How important is it for patients and families to be prepared for death?

What does delirium mean to you?

What is the impact of delirium here?

When someone is delirious, is that suffering?

What is your role in responding to suffering?

What role do medications play in the management of delirium?

How important is it to orient people?

What is it like to work with the families?

Does everyone who works here share the same philosophy? How important is that?

Appendix B: Research Ethics Board Approval and Renewal Certificates



Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Susan	Brajtman	Health Sciences / Nursingy	Supervisor
C.E. Betty	Cragg	Health Sciences / Nursingy	Co-investigator
Mary Ellen	Macdonald	Health Sciences / Nursingy	Co-investigator
David	Wright	Health Sciences / Nursingy	Student Researcher

File Number: H10-09-04**Type of Project:** PhD Thesis**Title:** Delirium and the Good Death: An Ethnography of In-patient Palliative Care

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
04/09/2010	04/08/2011	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:

N/A



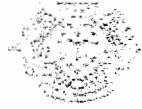
This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at: http://www.rges.uottawa.ca/ethics/application_dwv.asp

Please submit an annual status report to the Protocol Officer 4 weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at: http://www.rges.uottawa.ca/ethics/application_dwv.asp

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5841 or by e-mail at: ethics@uOttawa.ca.

Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the Health Sciences and Sciences REB



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at:
http://www.rges.uottawa.ca/ethics/application_dwn.asp

Please submit an annual status report to the Protocol Officer 4 weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at:
http://www.rges.uottawa.ca/ethics/application_dwn.asp

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5841 or by e-mail at: ethics@uOttawa.ca.


Protocol Officer for Ethics in Research
For Daniel Lagarec, Chair of the Sciences and Health Sciences REB



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Susan	Brajtman	Health Sciences / Nursing	Supervisor
C.E. Betty	Cragg	Health Sciences / Nursing	Co-investigator
Mary Ellen	Macdonald	Health Sciences / Nursing	Co-investigator
David	Wright	Health Sciences / Nursing	Student Researcher

File Number: H10-09-04

Type of Project: PhD Thesis

Title: Delirium and the Good Death: An Ethnography of In-patient Palliative Care

Renewal Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
04/09/2011	04/08/2012	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:

N/A

Appendix C: Hospice Caregiver Consent Forms



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Université d'Ottawa
Faculté des sciences
de la santé

École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences

School of Nursing

CONSENT FORM FOR HEALTH CARE PROFESSIONALS, STAFF AND VOLUNTEERS AT

Title of the study

**Delirium and the good death: An ethnography of in-patient
palliative care**

Student researcher: David Wright, RN, MSc(A), School of
Nursing, Faculty of Health Sciences, University of Ottawa.

Research supervisor: Susan Brajtman, RN, PhD, School of
Nursing, Faculty of Health Sciences, University of Ottawa

Introduction

You are invited to participate in a research study that is being conducted by David Wright in partial fulfilment of the requirements of his PhD program in Nursing at the University of Ottawa. You are being invited to participate because you are a healthcare professional, staff member, or volunteer at this palliative care facility.

Before deciding to participate in this study, it is important that you read the following information carefully and ask as many questions as necessary in order to clearly understand what your participation in this study involves. It is also important that you understand that you do not have to take part in this study. If you decide to participate, you will be asked to sign this consent form and a copy will be given to you.

Purpose of the study

The purpose of this research is to understand how cognitive impairment of patients (such as confusion, disorientation) at the end-of-life is experienced by families, healthcare providers, and patients themselves in palliative care. More generally, the purpose of this study is to understand the experiences of giving and receiving care in this residence and how such experiences affect the relationships between patients, their family members, and professional caregivers.

What participation involves

Participation in this study may involve different things. Each will be described below.

Participant-Observation:

If you consent to participate the student researcher (David Wright) will make observations of you during your normal day to day activities and interactions within this setting. These observations will not interfere with any patient care you are responsible for. In the course of observing the researcher will also engage in conversations with you. The student researcher will likely make notes (either during or after your interactions) based on these observations and conversations. At any time, you may tell the student researcher that you do not wish to speak with him for any reason. If at any time you feel that the presence of the student researcher is bothersome (to you or to your patients), you may ask him to leave the situation.

☐ I consent to allow David Wright to perform participant-observation

Initials _____

Interviews:

You may also be invited by the student researcher to participate in a personal interview, in which you will be asked questions about your experiences of providing end-of-life care to people with delirium at the end-of-life. If you agree, this interview will be audio-recorded. The student researcher will meet with you at times that are convenient for you. The interview will take place in a private room within the residence, and will last approximately 1 hour. The student researcher will likely only plan one interview with you, but if you would like the opportunity to meet more than once that is a possibility. At any point during the interview, you may take a break or stop the interview. If you choose to stop the interview, you may request that the information collected to that point be returned to you.

☐ I consent to interviews with David Wright

Initials _____

Risks: There is very little risk associated with participating in this study, as similar studies involving observations and interviews rarely cause any harm. It is possible that discussion

with the researcher about certain topics may upset you or cause you some distress. If that happens, you are at all times free to refuse to answer a specific question, end your discussion with the researcher for the time being, or withdraw from the study altogether. If you request additional support (immediately following the interview or anytime afterward), the clinical psychologist of this residence, , will be available to assist you and make any appropriate referrals for you. She can be reached at or by e-mail at .

Benefits: The benefits of this study will mostly be for future patients and family members who are admitted to residences such as this for palliative care. However, you may find it beneficial to engage in meaningful discussion about your practice and experiences.

Anonymity: Please be aware that your anonymity as a participant *within this residence* cannot be guaranteed, as other people will see you interacting with the researcher. However, any and all information that you provide to the student researcher will be kept strictly confidential. Results from this study will be published. Anonymity will be protected through no personal identifying information appearing in the researchers' presentations or published reports about the participants involved in this study.

Confidentiality: All information that you share during this study will remain strictly confidential. The student researcher will not disclose anything said to him to other participants or members of this residence without your express permission. All information that you provide will be made anonymous by the researcher through the use of codes. Your name will not appear in his personal notes or in transcripts of audio-taped interviews. The only people who will have access to any of the data (notes, transcripts) from this study are the student researcher, his primary research supervisor (Dr. Susan Brajtman), and members of his thesis committee (Drs. Betty Cragg and Mary Ellen Macdonald).

Conservation of Data: During the study, all notes and transcripts will be kept in a locked filing cabinet and/or a password protected computer in the office of David Wright. Once the study is completed, all data will be kept in a locked filing cabinet and/or password protected computer in the office of Susan Brajtman for a period of five years and will then be destroyed.

Voluntary Participation: You are under no obligation to participate in this study and if you agree to participate, you may withdraw from this study at any time. You may also refuse to answer any questions without any consequence to yourself. **Your participation in this study will in no way affect your status as an employee, professional, or volunteer.** If you choose to withdraw, you may request that all data collected until the time of withdrawal be destroyed or returned to you.

If you have any further questions or concerns you can contact the student researcher:

David Wright, RN, MSc(A), PhD candidate
School of Nursing, University of Ottawa

Or his supervising professor:

Susan Brajtman, RN, PhD
School of Nursing, University of Ottawa

If you have any questions about the ethical conduct of this study, you may contact the protocol officer for ethics in research at the University of Ottawa:

Protocol Officer for Ethics in Research

I, _____, voluntarily agree to participate in this study. I understand that I can withdraw at any time without any consequence. I have been explained the details of my participation and have had the opportunity to ask questions. If I had questions these have been answered to my satisfaction. I have been given a copy of this consent form to keep for my personal record.

In signing this form I also certify that I am *not* a minor (0-17 years old).

There are two copies of the consent form, one of which is mine to keep.

(Participant's Signature)

(Date)

Role of participant (e.g, nurse, physician, volunteer...)

(Student Researcher's Signature)

(Date)



uOttawa

FORMULAIRE DE CONSENTEMENT DES
PROFESSIONNELS DE LA SANTÉ, LE PERSONNEL, ET
LES BÉNEVOLES, 1

Titre de l'étude

**Le delirium et l'expérience d'une mort paisible: une
ethnographie en soins palliatifs spécialisés**

Université d'Ottawa
Faculté des sciences
de la santé

École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences

School of Nursing

Chercheur étudiant : David Wright, Inf., MSc(A), École des
sciences infirmières, Faculté des sciences de la santé,
Université d'Ottawa

Superviseur de la recherche : Susan Brajtman, Inf, PhD,
École des sciences infirmières, Faculté des sciences de la santé,
Université d'Ottawa

Introduction

Vous êtes invité(e) à participer à une étude de recherche menée
par David Wright en vue de la rencontre des exigences
partielles de son programme de doctorat en sciences infirmières
à l'Université d'Ottawa. Votre participation est sollicitée en
qualité de professionnel de la santé, un membre du personnel,
ou un bénévole à la Résidence de soins palliatifs de l'ouest de
l'île.

Avant de décider de participer à cette étude, il est important
que vous preniez connaissance des informations qui suivront.
Par la suite, vous êtes invité(e) à poser toutes les questions
nécessaires afin de comprendre clairement ce que votre
participation à cette étude implique. Vous pouvez bien entendu
choisir de ne pas participer à l'étude. Si vous décidez de
participer, il vous sera demandé de signer ce formulaire de
consentement dont une copie vous sera remise.

Objet de l'étude

Le but de cette recherche est de comprendre comment les
familles, les prestataires de soins et les patients eux-mêmes
vivent l'expérience de divers troubles cognitifs présents en fin

de vie chez un individu malade, telles que la confusion et la désorientation. Dans une perspective plus large, cette étude cherche à mettre en lumière comment à la fois les expériences de donner et de recevoir des soins au sein de cette résidence de soins palliatifs affectent les relations entre patients, membres de famille et soignants professionnels.

Ce que la participation implique

La participation à cette étude peut impliquer plusieurs volets. Chacun de ces volets est détaillé.

L'Observation-Participante :

Si vous consentez à participer le chercheur étudiant (David Wright) fera des observations de vos activités quotidiens et interactions dans le contexte de cette résidence. Ces observations n'interféreront pas avec les soins que vous donnez. Au cours de l'observation, le chercheur engagera aussi la conversation avec vous. Le chercheur étudiant prendra probablement des notes (soit pendant ou après vos interactions) basées sur les observations et les conversations. À tout moment et sans raison particulière, vous pourrez dire au chercheur étudiant que vous ne souhaitez pas lui parler. À n'importe quel moment, si vous sentez que la présence du chercheur étudiant est gênante (pour vous ou pour vos patients), vous pourrez lui demander de quitter la situation.

☐ Je consens à ce que David Wright effectue une observation participante.

Initiales _____

Entrevues :

Vous pouvez aussi être invité par le chercheur étudiant à participer à une entrevue individuelle au cours de laquelle il vous posera des questions sur vos expériences de donner des soins de fin de vie aux patients avec un délirium. Si vous acceptez, cette entrevue sera enregistrée sur une bande sonore. Le chercheur étudiant vous rencontrera à un moment qui vous conviendra le mieux. L'entrevue aura lieu dans une salle privée de la résidence et durera environ une heure. Probablement, le chercheur étudiant ne planifiera qu'une seule entrevue avec vous mais si vous le souhaitez il vous sera possible de le rencontrer plus d'une fois. À tout moment durant l'entrevue vous pourrez faire une pause ou arrêter l'entrevue. Si vous

choisissez d'arrêter l'entrevue, vous pouvez demander que les renseignements recueillis à ce point vous soient retournés.

☐ Je consens à participer aux entrevues avec David Wright

Initiales _____

Risques : Les risques associés à la participation à cette étude sont minimes étant donné que les études incluant des observations et des entrevues ne causent aucun préjudice. Il est possible qu'une discussion portant sur certains sujets avec le chercheur puisse vous bouleverser ou vous causer une certaine détresse. Si cela se produit, vous êtes libre à tout moment de refuser de répondre à une question précise, de terminer momentanément votre discussion avec le chercheur ou de vous retirer complètement de l'étude. Dans le cas où vous demanderiez un soutien supplémentaire (soit immédiatement après l'entrevue ou à tout moment par la suite), la psychologue clinique de cette résidence, _____ sera disponible pour vous aider et pour établir toutes les références qui vous seraient appropriées. Elle peut être jointe au _____ ou par courriel : _____

Avantages : Les avantages découlant de la participation à cette étude seront principalement de contribuer à l'amélioration des soins autant pour les patients que pour leurs proches au sein de résidence spécialisées en soins palliatifs. De plus, les participants à des études similaires trouvent souvent bénéfique le simple fait de s'engager dans une discussion visant à chercher du sens à leur expérience.

Anonymat : Votre anonymat en tant que participant à cette étude ne peut être garanti au sein même de la résidence étant donné la possibilité d'être vu en interaction avec le chercheur. Cependant tous les renseignements que vous fournirez au chercheur étudiant seront gardés strictement confidentiels. Les résultats de cette étude seront publiés, mais l'anonymat sera protégée de façon à ce qu'aucune information personnelle permettant d'identifier les participants impliqués dans cette étude n'apparaisse dans les présentations des chercheurs ou dans les rapports publiés.

Confidentialité : Toutes les informations que vous partagerez durant cette étude demeureront strictement confidentielles. Le chercheur étudiant ne divulguera rien de ce qui aura été dit aux autres participants ou membres de cette résidence sans votre autorisation expresse. Toutes les informations fournies seront

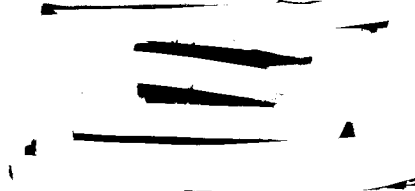
rendues anonymes par le chercheur grâce à l'utilisation de codes. Votre nom n'apparaîtra pas dans ses notes personnelles ou dans les transcriptions des entrevues enregistrées sur bande sonore. Les seules personnes qui auront accès aux données de cette étude (notes, transcriptions) sont le chercheur étudiant, son superviseur de recherche direct (Dr. Susan Brajtman) et les membres de son comité de thèse (Drs. Betty Cragg et Mary Ellen Macdonald).

Conservation des données : Pendant l'étude, toutes les notes et transcriptions seront conservées dans un classeur verrouillé et/ou dans un ordinateur protégé par un mot de passe dans le bureau de David Wright. Lorsque l'étude est terminée, les notes et transcriptions seront conservées dans un classeur verrouillé et/ou dans un ordinateur protégé par un mot de passe dans le bureau de Susan Brajtman, ceci pour une période de 5 ans et seront ensuite détruites.

Participation volontaire : Vous n'avez aucune obligation de participer à cette étude et si vous acceptez de participer, vous pouvez vous retirer à n'importe quel moment. Vous pouvez aussi refuser de répondre à n'importe quelle question sans qu'il n'y ait aucune conséquence pour vous-même. **Que vous participiez ou non, votre statut comme employé, professionnel, ou bénévole ne sera pas affecté.** Si vous choisissez de vous retirer, vous pouvez demander à ce que toutes les données recueillies jusqu'au moment du retrait soient détruites ou retournées.

Si vous avez des questions ou des préoccupations supplémentaires, veuillez contacter le chercheur étudiant :

David Wright, Inf., MSc(A), candidat PhD
École des sciences infirmières, Université d'Ottawa



Ou son professeur superviseur:

Susan Brajtman, Inf., PhD
École des sciences infirmières, Université d'Ottawa

Pour toute question concernant la conduite éthique de cette étude, vous pouvez contacter le bureau d'éthique à la Recherche de l'Université d'Ottawa :

Bureau d'éthique à la recherche

Je, _____, accepte volontairement de participer à cette étude. Je comprends que je peux me retirer à tout moment et sans aucune conséquence. Les détails de ma participation m'ont été expliqués et j'ai eu la possibilité de poser des questions. Lorsque j'ai posé des questions, celles-ci m'ont été répondues à mon entière satisfaction. J'ai reçu une copie de ce formulaire de consentement pour que je le garde dans mes dossiers personnels.

En signant ce formulaire, je certifie par la même occasion que je ne suis pas mineur (âgé de 0-17 ans).

Il existe deux exemplaires de ce formulaire de consentement dont l'un que je conserverai.

(Signature du Participant)

(Date)

Rôle du participant (ex. infirmière, médecin, bénévole...)

(Signature du Chercheur Étudiant)

(Date)

Appendix D: Patient Consent Forms



uOttawa

Université d'Ottawa
Faculté des sciences
de la santé
École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences
School of Nursing

CONSENT FORM FOR PATIENTS

AT

Title of the study

Delirium and the good death: An ethnography of in-patient palliative care

Student researcher: David Wright, RN, MSc(A), School of Nursing, Faculty of Health Sciences, University of Ottawa.

Research supervisor: Susan Brajtman, RN, PhD, School of Nursing, Faculty of Health Sciences, University of Ottawa

Introduction

You are invited to participate in a research study that is being conducted by David Wright in partial fulfilment of the requirements of his PhD program in Nursing at the University of Ottawa. You are being invited to participate because you are a patient who has been admitted to this palliative care residence for care.

Before deciding to participate in this study, it is important that you read the following information carefully and ask as many questions as necessary in order to clearly understand what your participation in this study involves. It is also important that you understand that you do not have to take part in this study. If you decide to participate, you will be asked to sign this consent form and a copy will be given to you.

Purpose of the study

The purpose of this research is to understand how cognitive impairment of patients (such as confusion, disorientation) at the end-of-life is experienced by families, healthcare providers, and patients themselves in palliative care. More generally, the purpose of this study is to understand the experiences of giving and receiving care in this residence and how such experiences affect the relationships between patients, their family members, and professional caregivers.

What participation involves

Participation in this study may involve different things. Each will be described in below.

Participant-Observation:

If you consent to participate, the student researcher will make observations in your hospital room and observe interactions between yourself, your family, and other health care providers who care for you. These observations will not interfere with the care you are receiving. In the course of observing the researcher will also engage in conversations with you. The student researcher will likely make notes (either during or after your interactions) based on these observations and conversations. At any time, you may tell the student researcher that you do not wish to speak with him for any reason. If at any time you feel that the presence of the student researcher is bothersome (to you or to your family), you may ask him to leave your room.

☐ I consent to allow David Wright to perform participant-observation

Initials _____

Interviews

You may also be invited by the student researcher to participate in a scheduled interview, in which you will be asked questions about your experiences at this residence including questions about your relationships with your family and with the people caring for you. If you agree, this interview will be audio-recorded. The student researcher will meet with you at times that are convenient for you. The student researcher will also check with your nurse to make sure that the timing for the interview is appropriate. If at the time of the interview you are tired or feeling unwell for any reason the student researcher will wait to conduct the interview at a time that you are feeling well enough to participate. The length of the interview will be determined by your interest, willingness, and energy level. The interview should not exceed one hour.

The student researcher will likely only plan one interview with you, but if you would like the opportunity to meet more than once that is a possibility. At any point during the interview, you may take a break or stop the interview. If you choose to

stop the interview, you may request that the information collected to that point be returned to you.

☐ I consent to interviews with David Wright

Initials _____

Chart Review

If you agree, the student researcher will also look at your medical chart. Information looked at and collected from the chart may include your diagnosis, your age, information on the history of your illness, and descriptions of the care you have received. Any information taken from the chart will be kept strictly confidential. Your name or any other identifying information will not appear in the notes of the student researcher or in any published results from this study.

☐ I consent to allow David Wright to look at my chart

Initials _____

Risks: There is very little risk associated with participating in this study, as similar studies involving observations and interviews rarely cause any harm. It is possible that discussion with the researcher about certain topics may upset you or cause you some distress. If that happens, you are at all times free to refuse to answer a specific question, end your discussion with the researcher for the time being, or withdraw from the study altogether. If you request additional support (immediately following the interview or anytime afterward), the clinical psychologist of this residence, [REDACTED] will be available to assist you and make any appropriate referrals for you. If outside of business hours, you can also speak to your nurse for assistance.

Benefits:

The benefits of this study will mostly be for future patients and family members who are admitted to residences such as this for palliative care. However, participants in studies similar to this one often find it beneficial to engage in meaningful discussion about their experiences.

Anonymity: Please be aware that your anonymity as a participant *within this residence* cannot be guaranteed, as other people will see you interacting with the researcher. However, any and all information that you provide to the student

researcher will be kept strictly confidential. Results from this study will be published. Anonymity will be protected through no personal identifying information appearing in the researchers' presentations or published reports about the participants involved in this study.

Confidentiality: All information that you share during this study will remain strictly confidential. The student researcher will not disclose anything said to him to other participants or members of this residence without your express permission. All information that you provide will be made anonymous by the researcher through the use of codes. Your name will not appear in his personal notes or in transcripts of audio-taped interviews. The only people who will have access to any of the data (notes, transcripts) from this study are the student researcher, his primary research supervisor (Dr. Susan Brajtman), and members of his thesis committee (Drs. Betty Cragg and Mary Ellen Macdonald).

Conservation of Data: During the study, all notes and transcripts will be kept in a locked filing cabinet and/or a password protected computer in the office of David Wright. Once the study is completed, all data will be kept in a locked filing cabinet and/or password protected computer in the office of Dr. Susan Brajtman for a period of five years and will then be destroyed.

Voluntary Participation: You are under no obligation to participate in this study and if you agree to participate, you may withdraw from this study at any time. You may also refuse to answer any questions without any consequence to you or your family. **Whether you participate or not you and your family will receive exactly the same level of care.** If you choose to withdraw, you may request that all data collected until the time of withdrawal be destroyed or returned to you.

If you have any further questions or concerns you can contact the student researcher:

David Wright, RN, MSc(A), PhD candidate
School of Nursing, University of Ottawa

Or his supervising professor:

Susan Brajtman, RN, PhD
School of Nursing, University of Ottawa

If you have any questions about the ethical conduct of this study, you may contact the protocol officer for ethics in research at the University of Ottawa:

Protocol Officer for Ethics in Research

I, _____, voluntarily agree to participate in this study. I understand that I can withdraw at any time without any consequence. I have been explained the details of my participation and have had the opportunity to ask questions. If I had questions these have been answered to my satisfaction. I have been given a copy of this consent form to keep for my personal record.

In signing this form I also certify that I am *not* a minor (0-17 years old).

There are two copies of the consent form, one of which is mine to keep.

(Participant's Signature – (Date)
Patient or Patient's Proxy Decision Maker **)

If Proxy Decision Maker – Name and Relationship to the Patient

(Student Researcher's Signature) (Date)

** In the case of a proxy decision maker, the section on *Interviews* (page 2) does not apply. Only patients who are capable of providing informed consent (as determined by the treating physician or clinical psychologist) will participate in formal interviews with the student researcher.



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FORMULAIRE DE CONSENTEMENT DES PATIENTS

Université d'Ottawa
Faculté des sciences
de la santé

École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences

School of Nursing

Titre de l'étude

**Le delirium et l'expérience d'une mort paisible: une
ethnographie en soins palliatifs spécialisés**

Chercheur étudiant : David Wright, Inf., MSc(A), École des
sciences infirmières, Faculté des sciences de la santé,
Université d'Ottawa

Superviseur de la recherche : Susan Brajtman, Inf, PhD,
École des sciences infirmières, Faculté des sciences de la santé,
Université d'Ottawa

Introduction

Vous êtes invité(e) à participer à une étude de recherche menée par David Wright en vue de la rencontre des exigences partielles de son programme de doctorat en sciences infirmières à l'Université d'Ottawa. Votre participation est sollicitée en qualité de patient(e) ayant été admis(e) à la Résidence de soins palliatifs de l'ouest de l'île.

Avant de décider de participer à cette étude, il est important que vous preniez connaissance des informations qui suivront. Par la suite, vous êtes invité(e) à poser toutes les questions nécessaires afin de comprendre clairement ce que votre participation à cette étude implique. Vous pouvez bien entendu choisir de ne pas participer à l'étude. Si vous décidez de participer, il vous sera demandé de signer ce formulaire de consentement dont une copie vous sera remise.

Objet de l'étude

Le but de cette recherche est de comprendre comment les familles, les prestataires de soins et les patients eux-mêmes vivent l'expérience de divers troubles cognitifs présents en fin de vie chez un individu malade, telles que la confusion et la désorientation. Dans une perspective plus large, cette étude cherche à mettre en lumière comment à la fois les expériences

de donner et de recevoir des soins au sein de cette résidence de soins palliatifs affectent les relations entre patients, membres de famille et soignants professionnels.

Ce que la participation implique

La participation à cette étude peut impliquer plusieurs volets. Chacun de ces volets est détaillé.

L'Observation-Participante :

Si vous consentez à participer, le chercheur étudiant (David Wright) procédera à des observations dans votre chambre d'hôpital. Il observera vos interactions avec les membres de votre famille ainsi qu'avec les autres prestataires de soins de santé. Ces observations n'interféreront pas avec les soins que vous recevez. Au cours de l'observation, le chercheur engagera aussi la conversation avec vous. Le chercheur étudiant prendra des notes à propos des observations et des conversations dont il aura été témoin. Cela pourra se dérouler soit pendant ou soit après les dites interactions. À tout moment, vous pourrez indiquer au chercheur étudiant que vous ne souhaitez pas lui parler. De même, si à un moment vous sentez que la présence du chercheur étudiant est gênante, que ce soit pour vous ou pour votre famille, vous pourrez toujours lui demander de quitter.

☐ Je consens à ce que David Wright effectue une observation participante.

Initiales _____

Entrevues :

Vous pouvez aussi être invité par le chercheur étudiant à participer à une entrevue individuelle au cours de laquelle vous serez posées des questions sur votre expérience au sein de la résidence. Cette entrevue peut comprendre des questions à propos de vos relations avec votre famille et avec les personnes qui s'occupent de vous. Si vous acceptez, cette entrevue sera enregistrée sur une bande sonore. Le chercheur étudiant vous rencontrera à un moment qui vous conviendra le mieux. Le chercheur étudiant consultera aussi votre infirmier(ère) pour

s'assurer que l'entrevue se déroule à un moment approprié et qu'elle n'interfère pas avec vos soins. Si au moment prévu pour l'entrevue, vous vous sentez indisposé(e), le chercheur étudiant pourra convenir avec vous sans problème d'un autre moment afin de reprendre l'entrevue. La durée de l'entrevue sera déterminée par votre intérêt, votre volonté et votre niveau d'énergie. L'entrevue ne devrait pas dépasser une heure.

Le chercheur étudiant ne planifiera qu'une seule entrevue avec vous. Néanmoins si vous le souhaitez, il vous sera possible de le rencontrer plus d'une fois. À tout moment durant l'entrevue vous pourrez faire une pause ou arrêter l'entrevue. Si vous choisissez d'arrêter l'entrevue, vous pouvez aussi demander à ce que les renseignements recueillis jusqu'à ce point vous soient remis.

☐ Je consens à participer à une entrevue avec David Wright

Initiales _____

Revue de dossier :

Si vous acceptez de donner le consentement à ce que le chercheur étudiant ait accès à votre dossier médical, celui-ci y recueillera les informations suivantes pour fin de son étude : votre diagnostic, votre âge, des informations sur l'histoire de votre maladie, la description des soins que vous avez reçus. Toutes les informations extraites du dossier seront conservées de façon confidentielle. Votre nom ainsi que toutes autres informations pouvant vous identifier n'apparaîtront pas dans les notes de l'étudiant chercheur ou dans les résultats publiés de cette étude.

☐ Je consens que David Wright puisse avoir accès à mon dossier médical.

Initiales _____

Risques : Les risques associés à la participation à cette étude sont minimales étant donné que les études incluant des observations et des entrevues ne causent aucun préjudice. Il est possible qu'une discussion portant sur certains sujets avec le chercheur puisse vous bouleverser ou vous causer une certaine détresse. Si cela se produit, vous êtes libre à tout moment de refuser de répondre à une question précise, de terminer momentanément votre discussion avec le chercheur ou de vous

retirer complètement de l'étude. Dans le cas où vous demanderiez un soutien supplémentaire (soit immédiatement après l'entrevue ou à tout moment par la suite), la psychologue clinique de cette résidence. _____ sera disponible pour vous aider et pour établir toutes les références qui vous seraient appropriées. En dehors des heures de travail, vous pouvez aussi demander de support à votre infirmier(ère).

Avantages : Les avantages découlant de la participation à cette étude seront principalement de contribuer à l'amélioration des soins autant pour les patients que pour leurs proches au sein de résidence spécialisées en soins palliatifs. De plus, les participants à des études similaires trouvent souvent bénéfique le simple fait de s'engager dans une discussion visant à chercher du sens à leur expérience.

Anonymat: Votre anonymat en tant que participant à cette étude ne peut être garanti au sein même de la résidence étant donné la possibilité d'être vu en interaction avec le chercheur. Cependant tous les renseignements que vous fournirez au chercheur étudiant seront gardés strictement confidentiels. Les résultats de cette étude seront publiés, mais l'anonymat sera protégée de façon à ce qu'aucune information personnelle permettant d'identifier les participants impliqués dans cette étude n'apparaisse dans les présentations des chercheurs ou dans les rapports publiés.

Confidentialité: Toutes les informations que vous partagerez durant cette étude demeureront strictement confidentielles. Le chercheur étudiant ne divulguera rien de ce qui aura été dit aux autres participants ou membres de cette résidence sans votre autorisation expresse. Toutes les informations fournies seront rendues anonymes par le chercheur grâce à l'utilisation de codes. Votre nom n'apparaîtra pas dans ses notes personnelles ou dans les transcriptions des entrevues enregistrées sur bande sonore. Les seules personnes qui auront accès aux données de cette étude (notes, transcriptions) sont le chercheur étudiant, son superviseur de recherche direct (Dr. Susan Brajtman) et les membres de son comité de thèse (Drs. Betty Cragg et Mary Ellen Macdonald).

Conservation des données : Pendant l'étude, toutes les notes et transcriptions seront conservées dans un classeur verrouillé et/ou dans un ordinateur protégé par un mot de passe dans le bureau de David Wright. Lorsque l'étude est terminée, les notes et transcriptions seront conservées dans un classeur verrouillé et/ou dans un ordinateur protégé par un mot de passe

dans le bureau de Susan Brajtman, ceci pour une période de 5 ans et seront ensuite détruites.

Participation volontaire : Vous n'avez aucune obligation de participer à cette étude et si vous acceptez de participer, vous pouvez vous retirer à n'importe quel moment. Vous pouvez aussi refuser de répondre à n'importe quelle question sans qu'il n'y ait aucune conséquence pour vous-même ou pour votre famille. **Que vous participiez ou non, vous recevrez exactement le même niveau de soins.** Si vous choisissez de vous retirer, vous pouvez demander à ce que toutes les données recueillies jusqu'au moment du retrait soient détruites ou retournées.

Si vous avez des questions ou des préoccupations supplémentaires, veuillez contacter le chercheur étudiant :

David Wright, Inf., MSc(A), candidat PhD
École des sciences infirmières, Université d'Ottawa

Ou son professeur superviseur:

Susan Brajtman, Inf., PhD
École des sciences infirmières, Université d'Ottawa

Pour toute question concernant la conduite éthique de cette étude, vous pouvez contacter le bureau d'éthique à la Recherche de l'Université d'Ottawa :

Bureau d'éthique à la recherche

Je, _____, accepte volontairement de participer à cette étude. Je comprends que je peux me retirer à tout moment et sans aucune conséquence. Les détails de ma participation m'ont été expliqués et j'ai eu la possibilité de poser des questions. Lorsque j'ai posé des questions, celles-ci m'ont été répondues à mon entière satisfaction. J'ai reçu une copie de ce formulaire de consentement pour que je le garde dans mes dossiers personnels.

En signant ce formulaire, je certifie par la même occasion que je ne suis pas mineur (âgé de 0-17 ans).

Il existe deux exemplaires de ce formulaire de consentement dont l'un que je conserverai.

(Signature du Participant –
patient ou mandataire du patient *)

(Date)

(Si Mandataire, nom et relation au patient)

(Date)

Signature de l'étudiant chercheur

(Date)

* Si un mandataire du patient, la section sur entrevues (page 2) ne s'applique pas. Seuls les patients qui sont capables de consentir (déterminé par le médecin traitant ou psychologue) participeront à une entrevue formelle avec l'étudiant chercheur.

Appendix E: Family Consent Forms



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CONSENT FORM FOR FAMILY MEMBERS

A. _____

Title of the study

Delirium and the good death: An ethnography of in-patient palliative care

Student researcher: David Wright, RN, MSc(A), School of Nursing, Faculty of Health Sciences, University of Ottawa.

Research supervisor: Susan Brajtman, RN, PhD, School of Nursing, Faculty of Health Sciences, University of Ottawa

Introduction

You are invited to participate in a research study that is being conducted by David Wright in partial fulfilment of the requirements of his PhD program in Nursing at the University of Ottawa. You are being invited to participate because you are a family member of a patient who has been admitted to this palliative care residence for care.

Before deciding to participate in this study, it is important that you read the following information carefully and ask as many questions as necessary in order to clearly understand what your participation in this study involves. It is also important that you understand that you do not have to take part in this study. If you decide to participate, you will be asked to sign this consent form and a copy will be given to you.

Purpose of the study

The purpose of this research is to understand how cognitive impairment of patients (such as confusion, disorientation) at the end-of-life is experienced by families, healthcare providers, and patients themselves in palliative care. More generally, the purpose of this study is to understand the experiences of giving and receiving care in this residence and how such experiences affect the relationships between patients, their family members, and professional caregivers.

Université d'Ottawa
Faculté des sciences
de la santé
École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences
School of Nursing

What participation involves

Participation in this study may involve different things. Each will be described below.

Participant-Observation:

If you consent to participate and the patient does not object, the student researcher (David Wright) will make observations in the hospital room of the patient and observe interactions between the patient, family members and other health care providers. These observations will not interfere with the care the patient is receiving. At other times the student researcher will make observations in other areas of this setting (corridors, lounge, etc) and observe interactions between you and other health care providers. In the course of observing the researcher will also engage in conversations with you. The student researcher will likely make notes (either during or after your interactions) based on these observations and conversations. At any time, you may tell the student researcher that you do not wish to speak with him for any reason. If at any time you feel that the presence of the student researcher is bothersome (to you or to the patient), you may ask him to leave the situation.

☐ I consent to allow David Wright to perform participant-observation

Initials _____

Interviews:

You may also be invited by the student researcher to participate in a personal interview, in which you will be asked questions about your experiences at this residence and your perception of the patient's experiences, including questions about your relationships with each other and with the people caring for you. If you agree, this interview will be audio-recorded. The student researcher will meet with you at times that are convenient for you. The interview will take place in a private room within the residence, and will last approximately 1 hour. If you would prefer, you may choose to meet with the researcher outside of the residence for the interview, including your home or a public place where privacy and discretion can be assured. The student researcher will likely only plan one interview with you, but if you would like the opportunity to meet more than once that is a possibility. At any point during the interview, you may take a break or stop the interview. If

you choose to stop the interview, you may request that the information collected to that point be returned to you.

☐ I consent to interviews with David Wright

Initials _____

Risks: There is very little risk associated with participating in this study, as similar studies involving observations and interviews rarely cause any harm. It is possible that discussion with the researcher about certain topics may upset you or cause you some distress. If that happens, you are at all times free to refuse to answer a specific question, end your discussion with the researcher for the time being, or withdraw from the study altogether. If you request additional support (immediately following the interview or anytime afterward), the clinical psychologist of this residence, _____, will be available to assist you and make any appropriate referrals for you. She can be reached at _____ or by e-mail at _____. If outside of business hours, you can also speak to the patient's nurse for assistance. The patient's nurse can be reached 24 hours a day at _____.

Benefits: The benefits of this study will mostly be for future patients and family members who are admitted to residences such as this for palliative care. However, participants in studies similar to this one often find it beneficial to engage in meaningful discussion about their experiences.

Anonymity: Please be aware that your anonymity as a participant *within this residence* cannot be guaranteed, as other people will see you interacting with the researcher. However, any and all information that you provide to the student researcher will be kept strictly confidential. Results from this study will be published. Anonymity will be protected through no personal identifying information appearing in the researchers' presentations or published reports about the participants involved in this study.

Confidentiality: All information that you share during this study will remain strictly confidential. The student researcher will not disclose anything said to him to other participants or members of this residence without your express permission. All information that you provide will be made anonymous by the researcher through the use of codes. Your name will not appear in his personal notes or in transcripts of audio-taped interviews. The only people who will have access to any of the

data (notes, transcripts) from this study are the student researcher, his primary research supervisor (Dr. Susan Brajtman), and members of his thesis committee (Drs. Betty Cragg and Mary Ellen Macdonald).

Conservation of Data: During the study, all notes and transcripts will be kept in a locked filing cabinet and/or a password protected computer in the office of David Wright. Once the study is completed, all data will be kept in a locked filing cabinet and/or password protected computer in the office of Susan Brajtman for a period of five years and will then be destroyed.

Voluntary Participation: You are under no obligation to participate in this study and if you agree to participate, you may withdraw from this study at any time. You may also refuse to answer any questions without any consequence to yourself or to the patient. **Whether you participate or not the patient will receive exactly the same level of care.** If you choose to withdraw, you may request that all data collected until the time of withdrawal be destroyed or returned to you.

If you have any further questions or concerns you can contact the student researcher:

David Wright, RN, MSc(A), PhD candidate
School of Nursing, University of Ottawa

Or his supervising professor:

Susan Brajtman, RN, PhD
School of Nursing, University of Ottawa

If you have any questions about the ethical conduct of this study, you may contact the protocol officer for ethics in research at the University of Ottawa:

Protocol Officer for Ethics in Research

[REDACTED]

I, _____, voluntarily agree to participate in this study. I understand that I can withdraw at any time without any consequence. I have been explained the details of my participation and have had the opportunity to ask questions. If I had questions these have been answered to my satisfaction. I have been given a copy of this consent form to keep for my personal record.

In signing this form I also certify that I am *not* a minor (0-17 years old).

There are two copies of the consent form, one of which is mine to keep.

(Participant's Signature)

(Date)

(Student Researcher's Signature)

(Date)

I am the parent or legal guardian of a minor whom I also wish to participate in this study. I understand that all of the provisions as described in this form apply equally to child participants. Although I am providing consent on behalf of this child, he/she has also provided his/her assent to participate and I have been given a copy of that assent form.

(Name of the child/children for whom consent is being provided)

(Parent/Legal guardian signature)

(Date)



uOttawa

FORMULAIRE DE CONSENTEMENT DES MEMBRES DE LA FAMILLE, ■

Titre de l'étude

**Le delirium et l'expérience d'une mort paisible: une
ethnographie en soins palliatifs spécialisés**

Université d'Ottawa
Faculté des sciences
de la santé

École des sciences
infirmières

University of Ottawa
Faculty of Health
sciences

School of Nursing

Chercheur étudiant : David Wright, Inf., MSc(A), École des
sciences infirmières, Faculté des sciences de la santé,
Université d'Ottawa

Superviseur de la recherche : Susan Brajtman, Inf, PhD,
École des sciences infirmières, Faculté des sciences de la santé,
Université d'Ottawa

Introduction

Vous êtes invité(e) à participer à une étude de recherche menée
par David Wright en vue de la rencontre des exigences
partielles de son programme de doctorat en sciences infirmières
à l'Université d'Ottawa. Votre participation est sollicitée en
qualité de membre de famille d'un(e) patient(e) ayant été
admis(e) à la Résidence de soins palliatifs de l'ouest de l'île.

Avant de décider de participer à cette étude, il est important
que vous preniez connaissance des informations qui suivront.
Par la suite, vous êtes invité(e) à poser toutes les questions
nécessaires afin de comprendre clairement ce que votre
participation à cette étude implique. Vous pouvez bien entendu
choisir de ne pas participer à l'étude. Si vous décidez de
participer, il vous sera demandé de signer ce formulaire de
consentement dont une copie vous sera remise.

Objet de l'étude

Le but de cette recherche est de comprendre comment les
familles, les prestataires de soins et les patients eux-mêmes
vivent l'expérience de divers troubles cognitifs présents en fin
de vie chez un individu malade, telles que la confusion et la
désorientation. Dans une perspective plus large, cette étude
cherche à mettre en lumière comment à la fois les expériences
de donner et de recevoir des soins au sein de cette résidence de

soins palliatifs affectent les relations entre patients, membres de famille et soignants professionnels.

Ce que la participation implique

La participation à cette étude peut impliquer plusieurs volets. Chacun de ces volets est détaillé.

L'Observation-Participante :

Si vous consentez à participer et que le patient ne s'y oppose pas, le chercheur étudiant (David Wright) fera des observations dans la chambre d'hôpital du patient et observera les interactions entre le patient, les membres de la famille et les autres prestataires de soins de santé. Ces observations n'interféreront pas avec les soins que le patient reçoit. À d'autres moments, le chercheur étudiant se rendra dans d'autres endroits de cette résidence (corridors, salons de repos, etc.) et observera vos interactions avec d'autres prestataires de soins. Au cours de l'observation, le chercheur engagera aussi la conversation avec vous. Le chercheur étudiant prendra des notes à propos des observations et des conversations dont il aura été témoin. Cela pourra se dérouler soit pendant ou soit après les dites interactions. À tout moment, vous pourrez indiquer au chercheur étudiant que vous ne souhaitez pas lui parler. De même, si à un moment vous sentez que la présence du chercheur étudiant est gênante, que ce soit pour vous ou pour le patient, vous pourrez toujours lui demander de quitter.

☐ Je consens à ce que David Wright effectue une observation participante.

Initiales _____

Entrevues :

Vous pouvez aussi être invité par le chercheur étudiant à participer à une entrevue individuelle au cours de laquelle il vous posera des questions sur vos expériences dans cette résidence et sur vos perceptions de l'expérience du patient, y compris des questions sur vos relations avec le patient et avec les personnes qui s'occupent de vous. Si vous acceptez, cette entrevue sera enregistrée sur une bande sonore. Le chercheur étudiant vous rencontrera à un moment qui vous conviendra le mieux. L'entrevue aura lieu dans une salle privée de la

résidence et durera environ une heure. Si vous le préférez, vous pourrez choisir de rencontrer le chercheur à l'extérieur de la résidence pour l'entrevue, y compris à votre domicile ou dans un lieu public où l'intimité et la discrétion peuvent être garantis. Le chercheur étudiant ne planifiera qu'une seule entrevue avec vous. Néanmoins si vous le souhaitez, il vous sera possible de le rencontrer plus d'une fois. À tout moment durant l'entrevue vous pourrez faire une pause ou arrêter l'entrevue. Si vous choisissez d'arrêter l'entrevue, vous pouvez aussi demander à ce que les renseignements recueillis jusqu'à ce point vous soient remis.

☐ Je consens à participer à une entrevue avec David Wright

Initiales _____

Risques : Les risques associés à la participation à cette étude sont minimes étant donné que les études incluant des observations et des entrevues ne causent aucun préjudice. Il est possible qu'une discussion portant sur certains sujets avec le chercheur puisse vous bouleverser ou vous causer une certaine détresse. Si cela se produit, vous êtes libre à tout moment de refuser de répondre à une question précise, de terminer momentanément votre discussion avec le chercheur ou de vous retirer complètement de l'étude. Dans le cas où vous demanderiez un soutien supplémentaire (soit immédiatement après l'entrevue ou à tout moment par la suite), la psychologue clinique de cette résidence, _____ sera disponible pour vous aider et pour établir toutes les références qui vous seraient appropriées. Elle peut être jointe au (_____) ou par courriel : _____. En dehors des heures de travail, vous pouvez aussi demander de l'aide à l'infirmière du patient. L'infirmière du patient peut être atteinte 24h sur 24h au _____.

Avantages : Les avantages découlant de la participation à cette étude seront principalement de contribuer à l'amélioration des soins autant pour les patients que pour leurs proches au sein de résidence spécialisées en soins palliatifs. De plus, les participants à des études similaires trouvent souvent bénéfique le simple fait de s'engager dans une discussion visant à chercher du sens à leur expérience.

Anonymat: Votre anonymat en tant que participant à cette étude ne peut être garanti au sein même de la résidence étant donné la possibilité d'être vu en interaction avec le chercheur. Cependant tous les renseignements que vous fournirez au

chercheur étudiant seront gardés strictement confidentiels. Les résultats de cette étude seront publiés, mais l'anonymat sera protégée de façon à ce qu'aucune information personnelle permettant d'identifier les participants impliqués dans cette étude n'apparaisse dans les présentations des chercheurs ou dans les rapports publiés.

Confidentialité: Toutes les informations que vous partagerez durant cette étude demeureront strictement confidentielles. Le chercheur étudiant ne divulguera rien de ce qui aura été dit aux autres participants ou membres de cette résidence sans votre autorisation expresse. Toutes les informations fournies seront rendues anonymes par le chercheur grâce à l'utilisation de codes. Votre nom n'apparaîtra pas dans ses notes personnelles ou dans les transcriptions des entrevues enregistrées sur bande sonore. Les seules personnes qui auront accès aux données de cette étude (notes, transcriptions) sont le chercheur étudiant, son superviseur de recherche direct (Dr. Susan Brajtman) et les membres de son comité de thèse (Drs. Betty Cragg et Mary Ellen Macdonald).

Conservation des données : Pendant l'étude, toutes les notes et transcriptions seront conservées dans un classeur verrouillé et/ou dans un ordinateur protégé par un mot de passe dans le bureau de David Wright. Lorsque l'étude est terminée, les notes et transcriptions seront conservées dans un classeur verrouillé et/ou dans un ordinateur protégé par un mot de passe dans le bureau de Susan Brajtman, ceci pour une période de 5 ans et seront ensuite détruites.

Participation volontaire : Vous n'avez aucune obligation de participer à cette étude et si vous acceptez de participer, vous pouvez vous retirer à n'importe quel moment. Vous pouvez aussi refuser de répondre à n'importe quelle question sans qu'il n'y ait aucune conséquence pour vous-même ou pour le patient. **Que vous participiez ou non, le patient recevra exactement le même niveau de soins.** Si vous choisissez de vous retirer, vous pouvez demander à ce que toutes les données recueillies jusqu'au moment du retrait soient détruites ou retournées.

Si vous avez des questions ou des préoccupations supplémentaires, veuillez contacter le chercheur étudiant :

David Wright, Inf., MSc(A), candidat PhD
École des sciences infirmières, Université d'Ottawa

Ou son professeur superviseur:

Susan Brajtman, Inf., PhD
École des sciences infirmières, Université d'Ottawa

Pour toute question concernant la conduite éthique de cette étude, vous pouvez contacter le bureau d'éthique à la Recherche de l'Université d'Ottawa :

Bureau d'éthique à la recherche

Je, _____, accepte volontairement de participer à cette étude. Je comprends que je peux me retirer à tout moment et sans aucune conséquence. Les détails de ma participation m'ont été expliqués et j'ai eu la possibilité de poser des questions. Lorsque j'ai posé des questions, celles-ci m'ont été répondues à mon entière satisfaction. J'ai reçu une copie de ce formulaire de consentement pour que je le garde dans mes dossiers personnels.

En signant ce formulaire, je certifie par la même occasion que je ne suis pas mineur (âgé de 0-17 ans).

Il existe deux exemplaires de ce formulaire de consentement dont l'un que je conserverai.

(Signature du Participant)

(Date)

(Signature du Chercheur Étudiant)

(Date)

Je suis le parent ou le tuteur légal d'un mineur à qui je souhaite également de participer à cette étude. Je comprends que toutes les dispositions décrites dans le présent formulaire s'appliquent également aux enfants participants. Même si je fournis le consentement au nom de cet enfant, il/elle a également fourni son consentement à participer et j'ai reçu une copie de ce formulaire d'assentiment.

(Nom de l'enfant/des enfants pour lesquels un consentement est fourni)

(Signature du Parent/Tuteur légal)

(Date)