The Dissertation Committee for Jodi Lee Sacks Certifies that this is the approved version of the following dissertation:

For Their Patients: A Grounded Theory Study of Hospice Nurses Responding to Their Patients' Suffering

Committee:

Deborah Volker, Supervisor

Gayle Acton

Cherie Simpson

Jenenne Nelson

Cynthia Moffet

For Their Patients: A Grounded Theory Study of Hospice Nurses Responding to Their Patients' Suffering

by

Jodi Lee Sacks, B.S.N.; M.S.

Dissertation

Presented to the Faculty of the Graduate School of
The University of Texas at Austin
in Partial Fulfillment
of the Requirements
for the Degree of

Doctor of Philosophy

The University of Texas at Austin
May 2014

Acknowledgements

Finishing this dissertation brings me to a stopping point. And I feel overwhelmed by all it took and what everyone gave to me in order for me to be here. Stopping. For the first time, I am able to sit and consider all that has gone into this project. I feel intense gratitude for and towards the multitude of people who have been a part of my life during this time. Words simply cannot express what they have meant and continue to mean to me.

My participants were hospice nurses. I am thankful they trusted me enough to share their opinions, experiences, and stories with me. Many of them have surprised me by keeping in contact after their interview, checking in on me to see if there was anything else I needed and to offer encouragement.

I am extremely grateful for the encouragement and support of my dissertation chairperson, Dr. Deborah Volker. Her guidance and suggestions have been innumerable. I also want to acknowledge my committee members. Dr. Gayle Acton and Dr. Cherie Simpson supported me with their ongoing encouragement during my studies at UT Austin. Dr. Jenenne Nelson mentored me through my master's program and inspired me to really embrace nursing. Without her in my life, I would not be in nursing. Dr. Cynthia Moffet mentored me in hospice work and in building collaborative relationships. I am humbled by the time and energy she has given to me. Without the input and support of these individuals, I would not have been able to complete this project.

I am deeply grateful to my husband, John, for his continued patience and support during this time. I cannot number the ways he has helped make this journey more pleasant for me. He has made dinners, taken the dog to the vet, woken me up when I fell asleep at my desk, cleaned the house, made cookies, and kept me (somewhat) sane during this time. Thanks! You're the BEST!

During this time, I have also had the opportunity to love my mother. And this has been a boon. While working on this project, my mother's lung cancer returned and I have been able to sit with her, listening to her reminisces and concerns as she approaches the end of her life. I cannot begin to express the mixed emotions of having a daughter's heart and a clinician's eye as I watch her steadily lose ground. It has been a race to get this project done before she dies. Most of all though, I am thankful for this last bit of bittersweet time I share with her.

For Their Patients: A Grounded Theory Study of Hospice Nurses Responding to Their Patients' Suffering

Jodi Lee Sacks, Ph.D.
The University of Texas at Austin, 2014

Supervisor: Deborah Volker

The purpose of this study was to develop an inductive theory describing the process that hospice nurses use to identify and respond to their patients' suffering. Additionally, the study sought to describe the coping strategies that hospice nurses used when working with patients they considered to be suffering. By examining nurses' responses to suffering, this study is the first step in developing effective interventions to alleviate patient suffering and mitigate its consequences on the nurses caring for those patients. Additionally, by knowing the different strategies that nurses use to cope when working with suffering patients, nurse administrators could institute educational programs, build supportive environments, and develop policies to support nurses as they deal with these difficult clinical situations. This is especially important in a hospice environment where the registered nurse is the focal point for ensuring ongoing patient assessment and implementation of the interdisciplinary plan of care by the various team members.

Charmaz (2006) description of grounded theory methodology guided the study design and analysis. Participants identified and responded to their patients' suffering within the context of the nurse-patient relationship. Phases of the relationship included:

preparation, establishment, cultivation, maintenance, and letting go. The participants gained insight into the psychosocial and existential aspects of the patient’s psyches by cultivating the nurse-patient relationship. Within this relational context, the participants used a four-phase process: observation, issue assessment, suffering, and intervention to respond to their patient’s suffering. In addition to pain and other signs of physical suffering, the participants identified other aspects of suffering: role losses, the patient’s fear of the impending death, the patient’s aloneness, and the patient’s feelings of guilt or regret. Interestingly, suffering also was considered a family affair and could involve the loss of self-identity. While the participants recognized the importance of self-care, often they had difficulty naming strategies used to respond and cope with their patients’ suffering. Clinical supervision and emotional support through mentoring and practical guidance need to be further developed to help nurses cope with the complexity of feelings that arise when caring for dying people.

Table of Contents

List of Tables

List of Figures

Chapter 1: Study Overview

The cumulative effect of the technological advances within healthcare is that many adult patients and healthcare providers have a false belief that death can be avoided (Ferrell, 2006). Incredible resources are spent trying to avoid death. Individuals in their last year of life account for more than $157.4 billion annually in healthcare expenditures with 30% of Medicare expenditures spent on the 5% of beneficiaries who die each year (Centers for Medicare and Medicaid Services, 2012; Lorenz, Shugarman, & Lynn, 2006; Lynn, 2004; Zhang et al., 2009). In the United States (U.S.), hospice services, the only program designed to provide end of life (EOL) services, are reserved for individuals who (1) have a life expectancy of less than six months, and (2) forego all "curative" therapies. Approximately 42% of deaths in the United States are attended by hospice services (National Hospice and Palliative Care Organization, 2012).

Kahn and Steeves (1986) defined suffering as an individual's experience of threat to self and is the meaning given to events such as pain or loss. Suffering—one of the most debilitating conditions faced at EOL—is often clinically neglected resulting in uncontrolled pain, depression, and a paralyzing inability to move beyond the symptom experience (Boston, Bruce, & Schreiber, 2011). Physical symptoms may act as a springboard into the experiential aspects of suffering, which in turn increases physical distress (Sacks, 2013). Rarely are patient symptoms linked to patient suffering (Morse, 2001). Unfortunately, focusing solely on physical symptoms often results in poor quality of life (QOL), increased costs (e.g., financial, emotional), and patient suffering (Lynn, 2004; Zhang et al., 2009). Since healthcare providers' lack knowledge and interventions to alleviate suffering, they can unknowingly intensify and prolong suffering in patients during their EOL experience.

A core skill in caring for dying patients is the relief of suffering (Breaden, Hegarty, Swetenham, & Grbich, 2012; Ferrell & Coyle, 2008; Kahn & Steeves, 1994). However, minimal research addresses how nurses identify and respond to patient suffering (Boston et al., 2011; Bruce, Schreiber, Petrovskaya, & Boston, 2011; Martins & Basto, 2011; Rydahl-Hansen & Eriksen, 2009). Interestingly, none of this research is from the U.S., and many of these studies focused on how patient suffering affects nurses and other healthcare providers (Boston & Mount, 2006; Breaden et al., 2012; Mok et al., 2010; White, Wilkes, Cooper, & Barbato, 2004). This indicates that nurses do, at times, recognize and respond to their patients' suffering; however, no study has been conducted in the U.S. focusing on how hospice nurses identify and respond to patients' suffering.

An individual's attitudes, values, beliefs, and desires are shaped by the culture one grows up in and the culture one lives in. This enculturation provides meaning and shapes the individual's interpretation of an experience (Eues, 2007). While suffering is generally considered a human experience that may happen to anyone, it is unknown what aspects of suffering, if any, are culturally bound. Are there cultural aspects of what it is to suffer? And does culture influence suffering at EOL? If so, study findings from outside the U.S. may or may not be relevant to the EOL experience in the U.S. Additionally, findings from U.S. studies are important because they add to the international body of literature on suffering at EOL and may reveal dimensions of suffering that have yet to be reported. Currently, only one study by Martins and Basto (2011) from Portugal specifically examines the nurse intervention process for patients suffering at EOL.

It is not easy to witness or to remain in the presence of a person who is suffering; yet, this is the nurse's professional obligation. Psychiatric approaches such as meaning-centered psychotherapy, cognitive-behavioral intervention, or psycho-educational counseling aside, there are no frameworks to guide the care provided to suffering patients

(Boston et al., 2011). Studies have found that suffering is a misunderstood condition for which there is no consensus regarding appropriate treatment (Boston et al., 2011; Breaden et al., 2012; Kahn & Steeves, 1994). Contributing to this issue is the observation that some nurses engage in unhelpful behaviors in order to distance themselves from working with a patient’s suffering (Boston et al., 2011; Boston & Mount, 2006). While the lack of a formal evidence base to care for suffering patients at EOL is a factor, the nurse’s lack of personal coping strategies may also be a contributing factor.

The purpose of this study is to uncover (1) what U.S. hospice nurses characterize as patient suffering, (2) the process they use to respond (e.g., thoughts, emotions, actions, interventions) to their patients’ suffering, and (3) what they do to personally care for themselves or cope with their patients’ suffering. Grounded theory methodology, as described by Charmaz (2006), was used to guide the design and analyze the data. A purposive sample of hospice nurses from the San Antonio, Texas (TX) area was recruited. This study involved one-to-one interviews with 22 participants. The specific aims for this study were:

- **Aim 1**: To uncover what hospice nurses characterize as patient suffering.
- **Aim 2:** To uncover the process hospice nurses use to respond to their patients who are suffering.
- **Aim 3**: To describe hospice nurses’ personal coping strategies used when working with patients they perceive as suffering.

SIGNIFICANCE OF STUDY

As a profession, nursing has a historical mandate to relieve suffering (Ferrell & Coyle, 2008; Georges & Grypdonck, 2002). Through their care, nurses help patients to recover and maintain composure in the face of illness while coping with the vulnerability and uncertainty of life (Ferrell & Coyle, 2008; Wakefield, 2000). Through their frequent contact, nurses are the most likely discipline to encounter and recognize patient suffering. In order to respond appropriately, the nurse needs a knowledge base to understand suffering, how to intervene to alleviate suffering, and how to cope with their own reactions to their patients' suffering (Arman, 2007). This study is significant because: (1) the evidence base for effectively identifying and intervening in patients' suffering is sparse; (2) by purposefully addressing patient suffering, it is conceivable that a patient's quality of life (QOL) can be improved; and (3) healthcare system outcomes may be improved (i.e., decrease in unnecessary or unwanted treatments). By examining nurses' responses to suffering, information from this study could be used to develop interventions that hospice nurses could use to care for their patients who are suffering and also potentially provide insights into how these nurses personally cope with their patients' suffering.

Background

In 1982, Cassell published a landmark article making the distinction between physical distress and suffering. Cassell made three foundational observations in this area. First, the entire being experiences suffering, not just a body part or the mind. Second, suffering occurs when an individual perceives an impending threat to personal integrity and continues until the threat of disintegration passes or the person's integrity is restored in some other manner. Third, suffering occurs in relation to any aspect (i.e., the who I am) or role of the person.

Early conceptual work in the area of suffering led Kahn and Steeves (1986) to define suffering as the individual's experience of threat to self and is the meaning given to events such as pain or loss. From this early work, a framework developed theorizing that suffering is a process with an irrevocable past, unbearable present, and an incomprehensible future (Kahn & Steeves, 1995; Rodgers & Cowles, 1997). The source of suffering is embedded within an actual or perceived loss (Georges, 2008; Kahn & Steeves, 1986; Morse, 2001; Rodgers & Cowles, 1997). As this area developed, the role of what loss(es) mean took precedence over understanding the threat to self. Kahn and Steeves (1986) defined self as that which the individual perceives as necessary for continued existence in that identity. This identity is the individual's daily experience of "self-sameness."

Studies concerning patient suffering at EOL highlight several themes: physical symptom experience, psychological distress, emotional isolation, and identity changes (Abraham, Kutner, & Beaty, 2006; Bruce et al., 2011; Chio et al., 2007; Rydahl-Hansen, 2005; Sacks & Nelson, 2007; Sand & Strang, 2006; Williams, 2004). The sufferers paid attention to their physical symptoms, often putting life tasks on hold and attributing negative meanings to the symptom that, in turn, increased their psychological distress. Unrestrained concern about their physical symptoms and current life circumstances consumed emotional energy and decreased their ability to cope; which increased their sense of uncertainty and situational vulnerability. As the psychological distress increased in the presence of declining functional ability and became linked to a sense of impending death, the sufferer experienced a devastating sense of isolation. Frequently, the sufferers perceived themselves as losing their self-identity and through the lens of "being a burden," they described changed roles and relationships. Ideally, if nurses could identify these themes in clinical situations, then they could be able to thoughtfully respond to them.

Overall, scant attention has been paid to how nurses identify and respond to patient suffering at EOL (Boston et al., 2011; Bruce et al., 2011; Martins & Basto, 2011;

Rydahl-Hansen & Eriksen, 2009). As a whole, these studies show that nurses do identify suffering at times and when they do identify suffering; they do not know what to do to alleviate the suffering. Another prevalent finding is the realization that the nurses are affected by their patients' suffering and may have personal difficulty coping with the situation. Even without a formal evidence base, nurses have developed strategies to respond to their patients' suffering at EOL. These strategies include pain/symptom management, trying to impart a sense of hopefulness to the patient, and being present with the sufferer.

Additionally, these same few studies indicate that working with suffering patients negatively impacts the nurse. Feelings of distress, sadness, failure, and "being overwhelmed" seem to be common experiences of nurses working with patients suffering at EOL. Nurses in these studies have shared various personal coping strategies: taking time off from work, exercise, hobbies, participation in religious activities, talking with other people, and that others had left working in EOL care settings. Importantly, being able to successfully deal with their patients' suffering is a motivator for the nurses to continue to work in EOL settings.

QOL Improvement

Suffering is a documented reason for why some individuals want to end their lives (Boston et al., 2011; Dees, Vernooij-Dassen, Dekkers, Vissers, & van Weel, 2011). A recent systematic review of suffering at EOL identified two areas where nurses could potentially intervene to ameliorate suffering (Sacks, 2013). First, suffering individuals perceived themselves as losing their identity as a known individual as others (including nurses) began relating to them (the sufferer) as an inanimate object. This objectification increased a sense of devastating aloneness, which made it very difficult for the sufferer to ask for help. Secondly, there was evidence that suffering played a role in the sufferer's symptom experience. Specifically, the emotional component of the suffering increased the perceived physical distress. As the sufferer spent more time ruminating about and attributing meaning (e.g., disease progression or "I am dying") to their physical experiences, their coping abilities decreased.

Unfortunately suffering is often neglected resulting in uncontrolled pain, increased depression and a paralyzing inability to move beyond the symptom experience (Boston et al., 2011). These physical symptoms exacerbate and are exacerbated by the suffering resulting in a poor QOL (Abraham et al., 2006; Boston et al., 2011; Dees et al., 2011; J. J. Georges & Grypdonck, 2002; Rydahl-Hansen & Eriksen, 2009; Sand & Strang, 2006). Since nurses lack clear direction for how to effectively alleviate suffering, they can unknowingly intensify and prolong the suffering experience.

Improved Patient Outcomes

Within healthcare, certain indicators are considered "good" outcomes while other indicators suggest "bad" outcomes. "Good" death outcomes generally include a peaceful home death where family and friends surround the patient and (ideally) hospice services are engaged. "Bad" death outcomes generally include a death where the patient physically struggles in a technologically complex, intensive care hospital connected to multiple tubes and wires, unable to speak, and alone except for hospital staff. Currently, the underlying assumptions seem to be that death is a medical failure and, if they must occur, then expensive deaths are a wasteful inappropriate use of resources. Ascertaining what encompasses a "good" death is certainly a challenge that is undergoing scrutiny; especially since it is unknown if money spent at EOL results in better EOL experiences for the patient (Eues, 2007; Ferrell & Coyle, 2008; Gruiner et al., 2007; Lorenz et al., 2006; Lynn, 2004). In contrast, a fundamentally accepted belief within the EOL care arena is the notion that good care empowers patients and families to be actively engaged in the decision making process (Eues, 2007; Gruiner et al., 2007; Lorenz et al., 2006; Lynn, 2004). Right or wrong, one benchmark indicator for this engagement is place of death. In a review of the literature, Gruiner et al. (2007) found multiple studies showing a consistent preference for Americans to die at home; this preference ranged from 59% to 90%. Yet, death at home occurs less than 25% of the time (Centers for Disease Control and Prevention & National Center for Health Statistics, 2012). Regardless of the shortcomings within the present system, it is reasonable to expect that for any individual, a good death would encompass the notion of the death occurring consistent with the individual's preferences. One of these preferences could be death occurring at patient's location of choice (e.g.; home, hospital, outside); instead of where an "expert" thought the death should occur. It is reasonable to hypothesize that an individual would have a greater ability to engage in his or her EOL experience (i.e., decision making) if that individual was not immobilized by suffering.

Most Americans now experience death from chronic illnesses (Centers for Medicare and Medicaid Services, 2012). In general, the healthcare system is geared towards diagnoses of and treatment of various diseases occurring within separate settings of care. Specialties are organized by body system with subspecialties focusing on one particular organ. This highly structured, hierarchical system creates communication barriers where various providers, acting in isolation, treat the body system/disease process without responding to the patient's overall condition (e.g., comorbidities, prescriptions, nutritional intake) or social factors (e.g., living arrangements, caregiver support). Thus, the individual may not be able to express personal values or preferences for place of death resulting in inefficient and inappropriate use of resources (e.g., medical treatments, hospice utilization/non-utilization, ventilator utilization, financial resources).

In summary, an understanding of the nurse's experience of patient suffering and the accompanying response (e.g., thoughts, emotions, actions, interventions) toward this suffering is important because such understanding can inform strategies to improve patient outcomes at the EOL. By examining nurses' responses to suffering, this study is the first step in developing effective interventions to alleviate suffering and mitigate its' consequences. Additionally, this project directly addressed (1) the National Institute of Nursing Research's (2011) strategic focus on EOL and palliative care science and (2) the Hospice and Palliative Nurses' research agenda (2012) to examine psychological and psychiatric aspects of care. Findings from this study on nurses' perspectives and during patients' suffering will help address these research goals.

THEORETICAL FRAMEWORK

The philosophical perspective guiding this study is symbolic interactionism (SI). Used to understand the relationship between an individual and society, SI is the theoretical underpinning of the grounded theory methodologies (Lambert & Lambert, 2010; Milliken & Schreiber, 2001). Symbolic interactionism facilitates the analysis of an emergent process occurring between the self and interaction with others by focusing on how meaning is constructed. In essence, the individual's communication is a mediator between the individual's observed behavior and the self's unseen thoughts. This provides a framework for understanding how an individual creates meaningful action from the context of one's lived reality over time.

According to SI, humans develop and depend on symbols (Charon, 2010). Symbols are the words, acts, and objects designed through social interaction that enables the individual to translate one's physical world into a personal reality that can then be shared with others. The symbol stands between the actual world and one's interpretation of reality. By manipulating symbols, the individual understands and interacts with others. The purpose of SI is to understand behavior by clarifying what objects and actions mean to the individual. Blumer (1969), relying chiefly on the thought and philosophical works of George Herbert Mead, outlines the assumptions of SI as:

- Individuals act toward things on the basis of the meanings of the objects that comprise their world.
- The meanings of objects are derived from the social interaction one has with other individuals.
- These meanings are expressed and modified through an interpretive process used by the individual in dealing with things that are encountered.

The purpose of this study was to uncover what hospice nurses characterize as patient suffering and the process they use to respond to this suffering. The nurse's viewpoint and actions toward a patient's situation is different from the patient's experience of that situation. It is through this nurse's viewpoint that the nurse provides care to the patient. SI provides a framework that links what the nurse identifies as "patient suffering" with how the nurse "thinks" about this suffering and subsequently does to address the suffering.

APPROACH

Study Design

The purpose of this study was to generate a theory describing the process of how hospice nurses identify and respond to their patients' suffering. Specifically, grounded theory methodology, as described by Charmaz (2006) was used to guide the design and analyze the data. Charmaz asserts that grounded theory methods provide systematic guidelines for collecting and analyzing data in order to construct theories that are "grounded" in the data themselves. Grounded theory is constructed through the researcher's interactions with the people and their perspectives, which acknowledges the resulting grounded theory is an interpretive portrayal of the process, not an actual schematic of the process. This makes grounded theory a methodology of choice in order to better comprehend how the nurses' subjective experiences related to the meanings of their patients' sufferings translates into the patterns and relationships used in responding to this suffering.

Assumptions

Assumptions about the epistemological basis of symbolic interactionism are described in the theoretical framework section of this chapter. Additional study assumptions include:

- Study participants will be able to identify suffering in their patients.
- Study participants will be willing to talk about these experiences of patient suffering.
- Study participants can and do intervene to mitigate suffering in their patients and families.
- While usually helpful, not all interventions benefit the patient or family.
- Witnessing patient suffering affects nurses. Sometimes, this witnessing results in a vicarious trauma to the nurse that affects subsequent interactions.
- Study participants will be able to identify personal coping strategies (e.g., exercise, talking to peers/family) that they consider personally helpful when working with suffering patients.

Definitions

The following definitions are presented to clarify terms used in this study:

Suffering.

Suffering is defined as an individual's experience of threat to self and is the meaning given to events such as pain or loss (Kahn & Steeves, 1986).

End of life.

Individuals living with advanced chronic diseases that require multiple hospitalizations due to life-threatening exacerbations or individuals with advanced age (e.g., older than 85 years) where a 1-3 year life expectancy is a reasonable estimate.

Hospice.

Hospice is a program of care to support individuals who are terminally ill with a prognosis of six months or less (U.S. Department of Health and Human Services & Centers for Medicare and Medicaid Services, 2013). Hospice services are geared to maintain the individual at their place of residence and focuses on provision of comfort. A team of interdisciplinary professionals (nurses, physicians, social workers, chaplains, nurses' aides, pharmacists, etc.) provides holistic care focused on the individual's comfort needs. This care includes physical care, counseling, medications, equipment, and supplies related to the hospice diagnosis and its related conditions.

Hospice Nurse.

An individual licensed to practice nursing (as a registered nurse or vocational nurse) and engaged in nursing practice within a hospice setting.

Limitations

Limitations of this study include issues related to the sample and also to the types of patients that these nurses care for. The sample was hospice nurses from the San Antonio, TX and surrounding area. This is a primarily Hispanic urban area in south Texas. The results may not be generalizable to other demographic areas; however, these findings provide a springboard to the development of formal theory when research is conducted in other populations. These nurses chose to work with a dying population. Their skill set may be different (e.g., pain management, communication with sensitive topics) and their contextual work environment may facilitate identifying suffering that otherwise would go unnoticed. Additionally, the "typical" hospice patient may be different (e.g., age, diagnoses, personal belief system related to death, caregiver availability) than patients not attended to by hospice services. These patient differences could influence what the nurses identify and respond to.

Chapter 2: Review of Literature

Through their care, nurses help patients to recover and maintain composure in the face of illness while coping with the vulnerability and uncertainty of altered futures (Ferrell & Coyle, 2008; Wakefield, 2000). Through their frequent contact, nursing is the most likely discipline to encounter and notice patient suffering. In order to respond appropriately, nurses working in EOL settings need a knowledge base to understand patient suffering at EOL, how to intervene to alleviate patients' suffering, and how to cope with their own reactions to their patients' suffering (Arman, 2007). This literature review provides an overview of studies informing the knowledge base of patient suffering at EOL and an overview of the studies informing the nurse's viewpoint of patient suffering at EOL.

PATIENT SUFFERING AT EOL

The studies reviewed in this section represent studies concerning patient suffering at EOL. Countries represented by these studies include Canada, Denmark, Finland, Japan, Netherlands, Sweden, Taiwan, Thailand, and the United States. Researchers drew participants from a variety of settings: clinics (i.e., hemodialysis, oncology), hospices, hospitals, nursing homes, and personal residences. The electronic databases PubMed (1982 – 2012), CINAHL (1982 – 2012), and PsychINFO (1982 – 2012) were searched for research studies concerning suffering at EOL. From the electronic searches, 115 research studies were identified as potentially relevant. After screening these articles and conducting ancestry searches of their references lists, 12 of these studies specifically focused on patient suffering at EOL. Interestingly, only one study was quantitative with a prospective cohort design. The remaining 11 studies utilized a range of qualitative designs: grounded theory, interpretive qualitative design, longitudinal qualitative design, and phenomenology in order to illuminate various aspects of suffering. While these studies began with different purposes, there is significant overlap in what the investigators attempted to accomplish. As a group, these studies explored the suffering experiences to include the nature, content, and meaning of suffering. Interesting aspects emerged such as the sufferer's intense feelings of isolation that could block communication with others, existential concerns related to suffering, factors affecting suffering, and whether healing (i.e., of relationships and emotional "wounds") could occur.

In a Finnish phenomenological study, Kuuppelomaki and Lauri (1998) endeavored to describe the nature, content, and meaning of suffering as reported by patients with incurable cancer. There study involved 32 patients with incurable cancer, 11 men and 21 women, drawn from two hospitals and four health centers. Their main findings included physical factors that primarily focused on the disease process and its treatment, psychological factors focusing on depression and fear of death, and a social factor centered around the restrictions and isolation brought about by the patient's unfolding circumstances. Additionally, the meaning of what the illness and treatments meant varied over the course of time.

Hagren, Pettersen, Severinsson, Lutzen, and Clyne (2001) sought to describe Swedish patients' experience of suffering from end-stage renal disease. Using an interpretive qualitative design, the researcher recruited 15 participants (seven men and eight women, ages 50-79 years) from a hemodialysis ward. The researchers identified the hemodialysis machine as a lifeline and alleviation of suffering as the two main themes. As part of the "hemodialysis machine as a life line" theme, the participants described loss of freedoms, increasing dependence on caregivers, and marital, family, and social relationships. In the "alleviation of suffering" theme the participants described gaining a sense of existential optimism and achieving a sense of personal autonomy by which the caregiver considered the participant as a valuable individual.

Using a content analysis framework, Morita et al. (2004) endeavored to categorize the existential concerns of Japanese terminally ill cancer patients. Recruitment for this study occurred from a specialized palliative hospital ward in Japan and included 88 participants (58 men and 30 women, ages 25-94 years). Interestingly, eight of the participants did not know of their time-limited prognosis at the time of the interview. Major categories of concerns included relationship concerns, loss of control, becoming a burden to others, loss of continuity (i.e., loss of being oneself, loss of roles), uncompleted life tasks, hope/hopelessness, and acceptance/preparation for dying.

In a United States (U.S.) study, Williams (2004) examined the experience of existential suffering among low-socioeconomic patients dying from cancer. Using a grounded theory methodology, the researcher recruited 33 participants (10 men and 23 women, ages 20-72 years) from an oncology clinic associated with a public hospital. Central to these participants' experience was the notion of dying "off time" that formed a terminal illness career. Dying "off time" referred to the participants' view that this was the wrong time to die. The dying career involved changes in the inner reality of the self and outer reality of how others interacted with the dying participant. These participants also experienced "anticipatory" suffering where the emotional labor of dealing with pain and (future) suffering preoccupied their affective ability to cope. And, finally, within this terminal illness career, the participant experienced a social isolation often described as a social death where there was a loss of equality in social exchanges, as the participant became an object to those around them.

Using Giorgi's descriptive phenomenology, Rydahl-Hansen (2005) endeavored to describe the experience of suffering among hospitalized cancer patients that had a life expectancy of less than two months. The researchers recruited six Danish women between the ages of 40-70 years. The researchers described six themes: increasing powerlessness, increasing loneliness, existing in an unconquerable struggle to regain control, being at the mercy of the body, being at the mercy of professionals, and finally, being at the mercy of the past, present, and future. Increasing powerlessness revolved around existing in an emotional chaos while constantly adapting to the body's and illness's increasing unpredictability. Increasing loneliness described the isolation experienced by being unable to express feelings and being surrounded by professionals, including nurses, who lacked the competence to care for psychosocial and existential concerns. Existing in a persistent unconquerable struggle to regain control centered on how the participants experienced their bodies as a threat causing them to feel insecure and fearful of losing more control. To be at the mercy of the body included how the participants experienced their body and its consciousness in relation to the disease, its treatment, and impending death. The researchers described to be at the mercy of the professionals as how the participants experienced their own inarticulateness around professional caregivers (nurses and physicians) who seldom had knowledge or time to cope with the participants' emotional concerns. And finally, to be at the mercy of the past, present and future, described how the participants' failing emotional and physical resources constricted their experience of time in a way that caused them to be fearful of the future and consequently, avoid initiating conversations about it.

In a Swedish study, Sand and Strang (2006) examined the experience of existential suffering and the origin of these feelings. Existential suffering was operationalized as existential isolation. Using an existential hermeneutics approach, the researchers recruited 40 participants (20 patients and 20 primary family caregivers; of the patients: 8 men and 12 women, ages 21-91 years) from a home-based palliative care service affiliated with a public hospital. The researchers reported an initial realization the participants had of the physical body as an alerting device that signaled a lethal illness and served to remind all involved that this was a very serious situation. The body's pathological changes revealed a reduced protection from life's circumstances. Changed life conditions and altered everyday experiences accompanied significant emotional changes and accentuated the body's declining condition. Overall, these new circumstances exposed an increasing vulnerability. Facets of this vulnerability included "not enough time," being ignored, inability to communicate, without information, separate ways between patient and caregiver, and the increasing responsibility of the primary caregiver (next of kin) to provide for all of the patient's needs.

Abraham et al. (2006) sought to identify differences in suffering between a group of U.S. hospice patients with physical symptom distress and a group of U.S. hospice patients with no physical symptom distress. In this prospective cohort design study (N=48), the researchers examined what factors (other than physical symptoms) affected the perception of suffering. In addition to numerically rating their severity of suffering (0-10 scale; 0 = no suffering, 10 = extreme suffering), participants completed a condensed Memorial Symptom Assessment Scale (MSAS), McGill Quality of Life Questionnaire (MQOL), demographic data, and were rated on the Karnofsky Performance Scale (KPS). Overall, the researchers found that factors such as diagnosis, age, and quality of life effect the perception of suffering. Participants reporting moderate-severe overall suffering were more likely to have a non-cancer diagnosis, be a younger age, and have lower scores on the MQOL-psychological subscale. Participants who reported worse overall suffering also reported worse suffering caused by physical symptoms. And, importantly, patients without physical symptoms also reported significant suffering.

Understanding the lived experiences of suffering and the change mechanism in healing processes among Taiwanese patients with terminal cancer, Chio et al. (2007) drew on the experiences of 21 oncology patients (8 men and 13 women, ages 37-76 years) hospitalized for their EOL care. These researchers identified three “plots” in this hermeneutic phenomenological study for describing how the participants identified suffering and healing. These plots were based on whom the individual relied upon: self, others, or a combination of self and others. For individuals who solely relied on themselves, suffering encompassed feeling distress due to the physical pain, thoughts about dying, and lack of support. For this group, healing seemed mostly passive and was oriented towards life meanings. In the group that solely relied on others, suffering also included feelings of fearing death and guilt for being a burden to one’s family. This group experienced healing differently—sensing feelings of protection through religious practices and being empowered by encouraging remarks of others. The individuals within the group that relied on self and others experienced all of the feelings previously mentioned in the suffering plots and also dealt with a measure of self-blame for doing “wrong” things and feeling hopeless because they lacked support. For the group who relied on self and others, healing encompassed feelings of relief when they could be present in the moment and the ability to gain positive views of life meanings through their religious practices. This last group also experienced a self-transcendence when they were able to help other cancer patients.

Sacks and Nelson (2007) examined participants experiences of nonphysical suffering and what was helpful to them during that time in a population of U.S. hospice patients. Using a grounded theory methodology, the researchers recruited 18 chronically ill participants (8 men and 10 women; ages 48-90 years) from various hospice settings (e.g., homes, residential hospice, nursing home). The core variable was trust; which was defined as a confidence in one's self-knowledge and perceptions of reality that enabled the individual to believe life events would meaningfully integrate into the individual's life experiences with a minimum of emotional discomfort. Once the individual acknowledged a break between their perceived and actual reality, this trust, mitigated by the individual's belief system, fluctuated dynamically and emotionally impacted the individual. As the individual lost trust in their self-knowledge, the individual experienced increased vulnerability, uncertainty, loss, and mistrust of others. In order to regain this self-trust, the individual spent a great deal of emotional and mental energy trying to control and cope with the current situation.

Nilmanat et al. (2010) sought to describe the suffering that patients with advanced terminal cancer in Thailand experience in their everyday life. The researchers recruited 15 participants (4 men and 11 women, ages 32-72 years) with terminal cancer diagnoses who were living at home to participate in a longitudinal, qualitative study. The study followed the participants from time of enrollment to death. The number of interviews with each participant ranged from four to fourteen. The researchers identified "living with suffering" as the overriding theme that included physical symptom distress, sense of worthlessness, sense of burdening others, and desire for a hastened death. Physical symptom distress impacted daily activities and limited functional abilities coupled with altered body images led to social isolation and feelings of alienation. Increasing dependency brought on a sense of worthlessness that many described as losing the value of being human. As the individuals became more dependent, they sensed the burden their living placed on others and attempted to conceal any suffering and minimize their needs. Many in this study also desired for their death to occur. While this longing was not constant, it was a desirable end to the "unbearableness" of suffering.

Bruce et al. (2011) examined the process of how Canadian individuals engaged with their existential suffering at EOL. The researchers recruited 22 participants (6 cancer patients, 6 family caregivers, and 10 healthcare professionals; gender and ages not stated) for this grounded theory study. Longing for ground in a groundless world was identified as the core variable and resulted from the suffering individual "being shaken to one's core." Within this study, engaging groundlessness meant turning toward the discomfort of groundlessness in an effort of learning to let go. Taking refuge in the habitual described how the participants also turned away from the discomfort by clinging to what was familiar to them. And finally, living in-between described how the participants created a balance within the groundlessness by potentially creating a short-lived comfort.

Dees et al. (2011) explored the constituent elements of suffering in Dutch patients that requested euthanasia or physician assisted suicide (PAS) in order to understand what constituted "unbearable suffering" from the participants' perspective. The researchers used grounded theory methodology to recruit 31 participants (14 men and 17 women, ages 32-94 years) who had requested euthanasia or PAS. Twenty participants had their requests granted and 11 of them were denied. Within the medical context, suffering originated in the symptoms of illness and its treatment or aging and included physical, cognitive, and psychiatric components. Findings prevalent in the psycho-emotional context included loss of self, loss of autonomy, mental exhaustion, negative feelings, and fear of future suffering. The socio-environmental context provided insights regarding loss of social significance, loneliness, communication difficulties, being a burden, and discontent with residential circumstances. Within the existential context, participants described a loss of pleasurable activities, hopelessness, and being tired of life.

Discussion of Patient Suffering at EOL

When considering these studies as a whole, several themes are consistently evident: physical symptom experience, psychological distress, emotional isolation, and identity changes.

Symptom experience

Across the studies, authors repeatedly reported that participants paid attention to their physical symptoms. Attending to what was happening within their bodies started dominating their life experience, forcing the participants to put other life tasks “on hold.” Specifically, the participants tried to make sense of what the symptoms meant in terms of disease process, treatment, and/or nearness of impending death. In addition to the physical distress, the symptoms also increased psychological distress.

Psychological distress

Within these studies, the physical experience seemed to be part of what initiated and exacerbated suffering; however, this may be an artifact of how interviews unfolded or how data analysis proceeded since the Abraham et al. (2006) and the Williams (2004) studies also described suffering in the presence of low physical symptom burden. Regardless, it is clear that the participants spent considerable time ruminating on the symptoms, their life circumstances, and what it all meant. Consuming all available emotional energy, this unrestrained concern often overwhelmed participants coping abilities. Consequently, the participants experienced an increased uncertainty and vulnerability as circumstances unfolded and they became more physically debilitated and experienced increased physical distress.

Emotional isolation

From these studies, it seems that when the sufferer's psychological distress increases in the presence of declining functional ability and becomes linked to a sense of death occurring soon, the result is a devastating sense of isolation. This isolation seemed to occur even when the sufferer was in close proximity to others and being cared for by other people. In essence, the isolation experience mutes the sufferer. The sufferer could not make their needs known and when others failed to intuit what the sufferer needed, the sufferer often experienced feelings of worthlessness and sometimes a desire for a hastened death. Unable to engage with anyone, the sufferer's negative self-talk and increasing sense of powerlessness often led to the sufferer describing one's self differently.

Identity changes

Identity change(s) are evident across studies in that participants often experienced a disruption in their self-identity. Consistently, participants described being shaken to their core, changed inner realities, and repeatedly emphasized that they did not know who they were within the experience or why they were being singled out to suffer. Frequently, the participants perceived themselves as losing their identities as a known individual and reported that other people related to them as inanimate objects (i.e., a burden, something that others do something to). Through this lens of "being a burden," the participant described changed roles and relationships.

In summary, findings in these studies concerning suffering at EOL highlighted several themes: physical symptom experience, psychological distress, emotional isolation, and identity changes. The participants paid attention to their physical symptoms, often putting life tasks on hold and attributing negative meanings to the symptom that, in turn, increased their psychological distress. Unrestrained concern about their physical symptoms and current life circumstances consumed emotional energy and decreased their ability to cope; which increased their sense of uncertainty and situational vulnerability. As the psychological distress increased in the presence of declining functional ability and became linked to a sense of impending death, the participant experienced a devastating sense of isolation. Frequently, the participants perceived themselves as losing their self-identity and through the lens of "being a burden," they described changed roles and relationships. Ideally, if nurses could recognize these themes in clinical situations, then they could be able to thoughtfully respond to them.

NURSE'S VIEWPOINT OF PATIENT SUFFERING AT EOL

The seven studies reviewed in this section represent the subsection of the previously described literature search that concerns the nurse's viewpoint of patient suffering at EOL. Countries represented by these studies include Australia, Canada, Denmark, Hong Kong, Portugal, Finland, and Sweden. Researchers drew participants from various palliative inpatient units (hospital, free-standing/hospice) and palliative/hospice at-home services. All of these studies have been qualitative in nature utilizing qualitative descriptive, grounded theory, focus groups, and phenomenology. As a group, these studies highlight the nurses' ability to recognize suffering (even when they cannot name it), that they often do not know how to alleviate it, and that the nurses are often affected by their patients' suffering.

In qualitative descriptive study, White et al. (2004) endeavored to describe the impact of unrelieved suffering on Australian nurses (N=9) working with palliative patients. Findings from their nine participants suggested that suffering was often ignored because it was considered "unfixable" and the nurses used multiple words (e.g., distress, anxiety, anguish, passionate sadness, depression) to mean "suffering." The participants disclosed that their patients' suffering negatively impacted them (the nurses). The participants' perceived that suffering often exists in their patients and is unrelieved. This knowledge is a burden to the nurses often triggering feelings of distress, sadness, being overwhelmed, and "feeling like a failure." The nurses described difficulties placing boundaries around this burden so it negatively affected their home lives and personal relationships. Factors that influenced how impactful this was to the nurse included the nurse's clinical experience, how connected the nurse felt to the patient, and the nurse's personal stress level. The nurses also engaged in a variety of strategies to mitigate the personal impact of their patient's suffering. These strategies included garnering support in order to talk through their emotions, exercising, engaging in their own spiritual life, hobbies, and taking time off from work.

In a Canadian study, Boston and Mount (2006) used focus groups to explore how palliative caregivers conceptualize spiritual/existential domains of care and how patient suffering impacts the palliative caregivers' well-being. Two focus groups consisting of five members each met three times for two hours each time. Each member of the group had at least 10 years palliative experience and consisted of four nurses, three volunteers, one musical therapist, and two physicians. The researchers used Moustakas analytic process to analyze and interpret the data. A surprising finding to the researchers was the participants' overwhelming and urgent need to unburden themselves when asked about their experiences with patient suffering. Overall, the participants struggled to qualify "spirituality" and saw their role as creating openings for the sufferer to be heard. The participants discussed issues of transference and countertransference and difficulties associated with cumulative grief. They also shared the need to develop healing connections with others and overall saw themselves as "wounded healers." Of concern to the participants was the need to develop healing environments that would sustain caregivers so they could continue to cope with their patients' suffering.

Rydahl-Hansen and Eriksen (2009) examined how verbal cues/signs of suffering were expressed and responded to within a Danish palliative unit. The researchers recruited 12 patients with advanced cancer and 25 nurses working in a hospital's palliative care unit. The researchers used participant observations between the patients and nurses and also one-to-one interviews with the patients to ascertain their actual experiences of suffering. The participant-observation data was analyzed using Peirce's semiotic phenomenology grounded theory of actual and potential signs and Giorgi's phenomenological method was used to analyze the interview data. The main findings included potential and actual signs of suffering as expressed by the patients (with the nurses' responses) and the potential signs of suffering that the nurses sought to identify on their own initiative. The patients expressed potential and actual signs of suffering to the nurses in four different ways. First, the patient would express a potential sign (e.g. pain, nausea) but not attach any meaning to the sign. In this situation, the nurse did not ask the patient what the sign meant to the patient and the interaction ended. Second, the patient attempted to express a sign of suffering but the nurse "drowned out" the patient by focusing on different topics and only attending to the nurse's immediate task at hand. Third, the patient expressed a sign of suffering and offered a meaning for the sign. In response, the nurse asked for reasons for the sign/symptom in an effort to correct the physical cause. Fourth, the patient did not express any sign to the nurse, but once the nurse left the room spontaneously expressed emotional reactions to their suffering. Additionally, nurses often sought to identify potential signs of suffering on their own initiative. Curiously, they did not do this when the patient was "new" to them or early in any shift. And, they engaged in this behavior after exhausting attempts to rationally explain the sign.

Mok et al. (2010) explored the phenomenon of existential distress in advanced cancer patients from the perspective of healthcare professionals in Hong Kong. The researchers convened five focus groups that had a total of 23 participants. The participants included 13 nurses (with 1-16 years experience), two physicians, two occupational therapists, one physical therapist, one chaplain, and two social workers. The researchers used constant comparative analysis to interpret the data. The participants related the causal conditions for existential distress in their patients originated from the patients anticipating a negative future and failing to engage in meaningful activities and relationships that enabled multiple regrets to surface. In response, the caregivers sought to meet the patient's basic needs and establish a deeper rapport with the patient that would enable the caregiver to specifically address the negative perceptions the patient held. The participants acknowledged that the patient had to be open to the healthcare provider and the provider had to be self-aware, interested in the patient, and able to convey a sense of hopefulness to the patient. The participants related that being able to do this for their patients was a source of satisfaction and an on-going motivator for continuing to work with these patients.

In a Portuguese study, Martins and Basto (2011) sought to understand the intervention process nurses use to relieve suffering in their EOL patients. The researchers recruited 19 nurses, 9 patients, and 19 relatives from an oncology-palliative hospital unit to participate in this grounded theory study. The researchers identified patient accompaniment as the basic process for how nurses seek to alleviate patient suffering. This process began with the nurses perceiving the patient's suffering and then seeking to alleviate the suffering. Standing in between these two progressions of identifying and alleviating was the nurse's suffering with the patient. Nurses became aware of patient suffering through the patient's expressive signals, behaviors, and verbal expressions, which the nurse interpreted as the patient experiencing an awful, negative, unbearable struggle. In order to alleviate this suffering, the nurse essentially tried to help the patient live by providing physical comfort and to die by trying to satisfy last wishes. Interfering with a smooth transition from identifying suffering and alleviating suffering is the nurse's recognition that the patient's suffering also triggers suffering within the nurse. The researchers also postulated that as the nurse accompanies each suffering patient and becomes more self-aware of one's own suffering, the nurse will learn how to more effectively cope with suffering (patient's and nurse's own).

Breaden et al. (2012) explored Australian palliative care clinicians' experiences, perceptions, and management of refractory patient suffering. The researchers recruited 17 participants with at least two years palliative care experience. These participants included ten nurses, five physicians, one social worker, and one chaplain. The researchers used qualitative analysis within a social constructivism framework to analyze the data. The most significant finding was the participants assertion that when dealing with suffering patients, one's approach had to change from "fixing" the problem to "being with" the patient. The participants described difficulties with negotiating and maintaining boundaries and trying to hold a healthy perspective related to time and work tempo. The participants also expressed a need to accept living with certain paradoxes such as: a need to detach yet remain committed to being involved with the suffering patient; a need to become desensitized to the sufferer's distress while remaining compassionate; and a need to accept realistic limits while doing everything possible.

In a multinational study, Thorup, Rundqvist, Roberts, and Delmar (2012) endeavored to study nurses' experiences of how their own vulnerability and suffering influenced their ethical formation and ability to provide professional care to their suffering patients. The researchers recruited 23 participants with at least five years of work experience; eight from Denmark, seven from Finland, and eight from Sweden. Analysis and interpretation of the data was conducted in accordance with Steiner and Kvale's three levels of interpretation. The researchers found that the nurse's ethical formation occurs over time and is the union of the nurse's personal attributes and professional qualifications. Also, the experiences of vulnerability and suffering shape the nurse's courage in relation to the provision of care. Courage manifests through helping patients face their own vulnerability and suffering, bearing witness to patients' vulnerability and suffering, and trusting oneself to advocate and provide professional nursing care.

DISCUSSION OF NURSE'S VIEWPOINT OF PATIENT SUFFERING AT EOL

Overall, scant attention has been paid to how nurses identify and respond to their patients' suffering at EOL. As a whole, these studies show that nurses do identify suffering at times and when they do identify suffering; they do not know what to do to alleviate the suffering. Another prevalent finding is the realization that the nurses are affected by their patients' suffering.

While some of the studies seemed to indicate that nurses lack clarity concerning what suffering is, other studies indicate that nurses do know what suffering is and can clinically identify it. This inconsistency may be explained by the nursing discipline's overall lack of theoretical development within the area of suffering or clinician uncertainty regarding how to translate research findings into practical applications. Regardless, there is no clear evidence base for the nurses to use when identifying or alleviating patient suffering.

Even without a formal evidence base, nurses have developed anecdotal strategies to work with patient suffering at EOL. Consistently, nurses attempted to meet the basic physical needs of their suffering patients by attending to pain/symptom management and setting up the environment to accommodate the patient's particular needs at that time. Some of the nurses saw their role as journeying with the suffering patient and trying to create openings so the patient could share. Some nurses believed it was important that even in the sufferer's "dark" times that the nurse try to impart a sense of hopefulness to the patient or at least maintain a personal sense of hopefulness for the patient. An interesting perspective voiced by some of the nurses was that the nurse's focus had to change when dealing with patient suffering. Instead of "fixing" a problem (e.g. giving analgesics for pain), the nurse needed to learn to "be with" the patient in order to convey worth and dignity to the patient.

Additionally, these studies indicate that witnessing and working with suffering patients negatively impacts the nurse. Feelings of distress, sadness, failure, and "being overwhelmed" seem to be common experiences of nurses working with patients suffering at EOL. The nurses clearly had a need to talk and share what happens to them when they work with suffering patients and the cumulative grief they continually experienced. The researchers often reported the nurses suggesting that they needed emotional support and someone to talk to in order to process what they experience in relation to the patient's suffering. Researchers frequently reported that the nurses had difficulty maintaining boundaries between caring for their suffering patients and their personal lives. Caring for these patients often is overwhelming. The nurses shared various coping strategies: taking time off from work, exercise, hobbies, participation in religious activities, talking with other people, and some left working in EOL care settings. Importantly, being able to successfully deal with their patients' suffering is a motivator for the nurses to continue to work in EOL settings.

Gap in the Literature

Suffering is an individual's experience of threat to self and is the meaning given to events such as pain or loss (Kahn & Steeves, 1986). Unfortunately, minimal research addresses how nurses identify and respond to patient suffering, and none of the reviewed studies focused on nurses practicing in the U.S. Previous studies have found that suffering is generally not talked about in the clinical environment because there is uncertainty concerning what suffering is, and lacking a physiological explanation, it is considered "unfixable." Thus, suffering may be witnessed and left unaddressed thereby exacerbating the patient's suffering. Contributing to this issue is the observation that some nurses engage in unhelpful behaviors in order to distance themselves from working with a patient's suffering. While the lack of a formal evidence base to care for suffering patients at end of life is a factor, the nurse's lack of personal coping strategies may also be a contributing factor. Also, study findings from outside the U.S. may or may not be relevant to providing EOL nursing care within the U.S. healthcare culture and context. As such, findings from U.S. studies are important because they add to the international body of literature regarding EOL nursing care in the U.S. and may reveal dimensions that have yet to be reported. Therefore, the purpose of this study was to uncover (1) what U.S. hospice nurses characterize as patient suffering, (2) the process they use to respond (e.g., thoughts, emotions, actions, interventions) to their patients' suffering and (3) what they do to personally care for themselves or cope with their patients' suffering.

Conclusion

It is not easy to witness or to remain in the presence of a person who is suffering; yet, this is the nurse's professional obligation (Newman, Sime, & Corcoran-Perry, 1991). Psychiatric approaches aside, there are no frameworks to guide the care provided to suffering patients (Boston et al., 2011). By examining nurses' responses to suffering, this study is the first step in developing effective interventions to alleviate patient suffering and mitigate its consequences on the nurses caring for those patients. Additionally, by knowing the different strategies that nurses use to cope when working with suffering patients, nurse administrators could institute educational programs and develop policies to support nurses as they deal with these difficult clinical situations. This is especially important in a hospice environment where the registered nurse is the focal point for ensuring ongoing patient assessment and implementation of the interdisciplinary plan of care by the various team members. If this nurse is unable or unwilling to identify and respond to the patient's suffering, the hospice team may not address this debilitating condition.

Chapter 3: Methods

METHOD

The purpose of this study was to generate a theory describing the process of how hospice nurses identify and respond to their patients' suffering. Specifically, grounded theory methodology, as described by Charmaz (2006) was used to guide the design and analyze the data. Charmaz asserts that grounded theory methods provide systematic guidelines for collecting and analyzing data in order to construct theories that are "grounded" in the data themselves. Grounded theory is constructed through the researcher's interactions with the people and their perspectives, which acknowledges the resulting grounded theory is an interpretive portrayal of the process, not an actual schematic of the process.

THEORETICAL FRAMEWORK

The philosophical perspective guiding this study is symbolic interactionism (SI). Used to understand the relationship between an individual and society, SI is the theoretical underpinning of the grounded theory methodologies (Lambert & Lambert, 2010; Milliken & Schreiber, 2001). SI facilitates the analysis of an emergent process occurring between the self and interaction with others by focusing on how meaning is constructed. In essence, the individual's communication is a mediator between the individual's observed behavior and the self's unseen thoughts. This provides a framework for understanding how an individual creates meaningful action from the context of one's lived reality over time.

Assumptions

Since symbolic interactionism provides the theoretical framework for the grounded theory methodologies, it is necessary to understand SI’s assumptions. According to SI, humans develop and depend on symbols (Charon, 2010). Symbols are the words, acts, and objects designed through social interaction that enables the individual to translate one’s physical world into a personal reality that can then be shared with others. The symbol stands between the actual world and one’s interpretation of reality. By manipulating symbols, the individual understands and interacts with others. The purpose of SI is to understand behavior by clarifying what objects and actions mean to the individual. Blumer (1969), relying chiefly on the thought and philosophical works of George Herbert Mead, outlines the assumptions of SI as:

- Individuals act toward things on the basis of the meanings of the objects that comprise their world.
- The meanings of objects are derived from the social interaction one has with other individuals.
- These meanings are expressed and modified through an interpretive process used by the individual in dealing with things that are encountered.

From examining these assumptions, several implications of SI become apparent. First, reality is social in nature and determined through the individual’s interactions with other people. Second, individuals do not sense their environment directly; they define the situation they are in. This allows the individual to live in a physical reality, a social reality, and a private, internal reality. Third, human action and social interaction always occur in the present. Over the course of time, a line of action oriented towards an object becomes apparent. This provides for societal stability and cultural change. And, fourth, changing the meaning of an object will change how the actor acts toward the object.

Methodologically, SI requires the study of behavior in order to clarify what objects mean to the various actors since it is through interaction that meaning is exposed. Essentially, grounded theory methodology is an approach where the researcher illuminates an interpretive understanding of the participants' world.

Considering Someone Else's Point Of View

Utilizing the notion of a "self" enables an individual to engage in a "self-talk" that permits the individual to consider how someone else will perceive and interpret a particular situation. Within this study, SI was used to provide the framework for how a nurse considers a patient's suffering (See Figure 1).

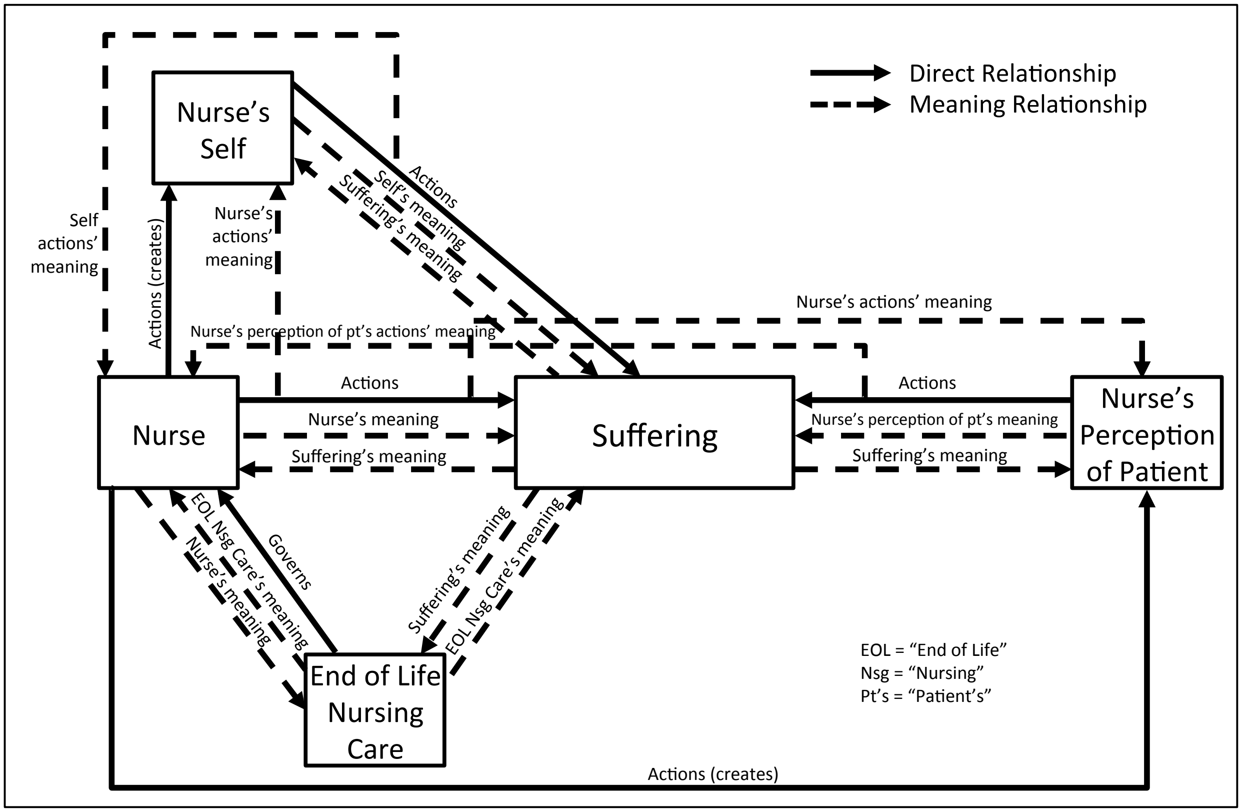


Figure 1. A Nurse Considering a Patient's Suffering

Beginning with the nurse making an indication to one's "self", the nurse creates a self that is a specialized kind of object that represents the nurse's internal world to the nurse. (This is the nurse's private, internal reality). The nurse then is able to treat this self as a different individual. Considering the self as a separate individual to make indications to enables the nurse to "talk to one's self" and to use these indications to guide actions. These self-actions are indications of what the nurse believes about one's self. Additionally, considering the self as another individual enables the nurse to consider other viewpoints. By utilizing the nurse's self, the nurse can then project how another individual (i.e., the patient) would perceive/interpret the situation in any particular social interaction. This projection is not the actual patient's viewpoint or reality, this projection is simply an image the nurse uses to consider how the patient might feel or act and what the patient actions could mean. This is how the nurse clarifies what one is thinking about, understands, or intends to do in relation to any object (e.g., suffering).

Explanation of Concepts

The primary concepts from SI used in this study are nurse, nurse's self, actions, suffering, nurse's perception of a patient, and end-of-life (EOL) nursing care. They are defined as follows:

- Nurse: an actor, possessing a nurse's license, with the capacity to make indications and interpret indications.
- Nurse's self: a specialized type of object that enables the nurse to make self-indications that guide self-actions. These self-actions are indicators of what the nurse believes about one's self.
- Actions: any gesture or act that has significance. Every action signifies what the person making the action intends to do, to whom the action is directed, and what

the accompanying action of the other person should be. Any act can be considered an object when it is isolated and defined according to the goals of the actor's present situation.

- Suffering: an object that can be indicated. Has a life cycle where the object's meaning is identified, sustained, transformed, weakened, and extinguished through the use of common meaning.
- Nurse's perception of patient: a specialized type of object that the nurse uses in the role of an actor in order to consider how the patient would feel or act in a situation.
- End-of-life nursing care: the context of all nursing care that occurs in the hospice setting considered as a collective whole that can create, affirm, transform, and extinguish suffering.

Explanation of Relationships

As part of sensing their environments, individuals define the situations they are in through the use of identifying symbols. This begins with a selective perception of objects within a situation and emerges out of social interaction with others and occurs in the present. These are the beginning relationships:

- An actor (nurse, nurse's self, nurse's perception of patient) directly acts on the objects (suffering).
- Society (EOL nursing care) directly governs the actor (nurse).
- There are multiple feedback loops between actors, suffering, and EOL nursing care that all involve interpretive meaning.

Direct relationships.

The direct relationships are shown with a solid line. Through the process of defining a situation, the actor directly acts upon an object. This means that the actor names the object and can manipulate it either physically or mentally such as when a nurse considers what suffering is.

Society governs an actor through teaching values, defining rules of conduct, demonstrating appropriate actions, and establishing laws, policies and procedures. Within this study, society is defined as "EOL nursing care" and it is through the nurse's understanding of "EOL nursing care" (i.e., society) that the nurse knows what suffering is, how to identify suffering, and what to do for the patient who is suffering.

Indirect (Meaning) relationships.

Within SI, feedback loops suggest various meanings that guide the way the nurse should act. A dashed line identifies these meaning loops.

Between nurse and suffering.

The meaning(s) a nurse holds towards suffering establishes the way the nurse should act towards suffering (i.e., that is the patient who is suffering).

Between suffering and EOL nursing care.

The relationship depicted from suffering to EOL nursing care provides the meaning of how the suffering is currently being recognized and indicates that suffering influences EOL nursing care. Additionally, the relationship from EOL nursing care to suffering suggests the professional viewpoint of the nursing profession's social norms and cultural mores with respect to suffering.

Between EOL nursing care and nurse.

The meaning relationship from EOL nursing care to the nurse conveys "EOL nursing care" meanings of the collective group life that are the social norms and cultural mores to the individual nurse. Thus, EOL nursing care (directly) governs the nurse's actions. The relationship from the nurse to EOL nursing care provides meaning to EOL nursing care through the degree of conformity to EOL nursing care's meanings and governance. This means the congruency between the nurse's actions and what "EOL nursing care" is understood to be is constantly being evaluated and either sanctioned or disapproved.

Between the nurse and the nurse's self

As previously stated, nurse creates a self that is a specialized kind of object that represents the nurse's internal world to the nurse. The nurse then is able to treat this self as a different individual. Considering the self as a separate individual to make indications to enables the nurse to "talk to one's self" and to use these indications to guide actions. These self-actions meanings are indications of what the nurse believes about one's self. Building on the nurse's self-interaction, the nurse can make self-indications about objects (e.g., suffering, patient, intervention) to one's self and the self can "respond." This is how an actor clarifies what one is thinking about, understands, or intends to do in relation to any object.

From Nurse's perception of the patient to suffering

When the nurse is forming a social-interaction, the viewpoint of the other actor (i.e., the patient) must be considered. In order to consider the patient's viewpoint, the nurse mentally constructs an image of the patient that is consistent with whom the nurse perceives the patient to be. As the nurse anticipates interacting act with patient, the meaning-feedback loops determine what the other patient's actions mean. This is how the nurse clarifies what one is thinking about, understands, or intends to do in relation to any object (e.g., suffering).

APPROACH

Grounded Theory Methodology

According to Charmaz (2006), grounded theory methodology is a research tool-kit used to construct theories "grounded" in the data themselves by employing a specific set of systematic, flexible guidelines when collecting and analyzing qualitative data. This type of research methodology is used when the researcher wants to understand the participants' interpretation of a particular issue such as a patient's suffering. Charmaz points out that grounded theory involves taking data comparisons and reaching up to form abstractions while simultaneously reaching down to link abstractions to the data. Data form the foundation of the theory and its analysis generates the concepts used to explain "what is going on here" from the participants' perspective.

Charmaz views grounded theory through a constructivist lens (2006). Essentially, this type of approach emphasizes the data and the analyses proceed from a shared construction of experiences and relationships between the participants and other data sources. As the phenomenon is studied, the participant and the researcher jointly interpret the phenomenon. Within this lens, the analysis is contextually situated in time, place, and situation. As the researcher begins to understand *how* participants construct meanings and actions in specific situations, then the researcher may be able to understand why the participants act as they do (Charmaz, 2006). Therefore, the resulting theory is an interpretation of what the research participants do and depends on the researcher's point of view. As such, grounded theory methodology is used to interpret how the nurses' subjective experiences related to the meanings of their patients' sufferings translates into the patterns and relationships used in responding to this suffering.

In contrast to a positivist approach to grounded theory (e.g., Glaser or Strauss and Corbin), a constructivist approach to grounded theory does not adhere to a positivist view of finding a single, basic social process or "core variable" (Charmaz, 2006). Instead, Charmaz asserts the constructivist view recognizes the multiple realities comprising the diverse local world, which is situated in and reflective of the larger world that encompasses it. Within this approach, the aim of the grounded theory methodology is to offer an interpretation of how participants construct and act on their personal realities.

Population

The population for this study was hospice nurses working in the San Antonio, TX area. By virtue of their work environment and patient population, hospice nurses can identify and work with their patients' suffering more openly than nurses in other clinical environments.

Sample

Participant selection was based on theoretical sampling (Charmaz, 2006). This means that participants were initially selected because they met specific inclusion criteria. For this project, the initial inclusion criteria were nurses (vocational or registered), currently employed in a hospice setting (for at least 3 months), and spoke English. While the nurse's licensure affects the scope of practice (i.e., tasks) that a nurse may perform, the experience of responding to patient suffering within the role of "hospice nurse" is the common denominator. Advanced practice nurses were excluded because they usually fill "provider" roles meaning they go to the house or the inpatient unit in the role of "physician" and are treated differently than staff nurses. While three months hospice experience is very little, almost all hospice nurses begin their hospice careers with multiple years of nursing experience acquired in other settings. The data from these initial participants served to identify and define categories. Based on the categories uncovered, further sampling was theoretically determined in order to develop and refine the categories in the emerging theory. This continued until the categories became saturated; which meant that no new data were emerging from participant interviews (Charmaz, 2006). Morse (2000) suggests that 20 to 30 participants may be needed for a grounded theory study of this scope.

Twenty-two hospice nurses participated in this study. Ages ranged from 37-70 years old. (See Table.) The median age was 57 years old and modal age was 59 years old. Eighteen of the participants were female and four participants were male. Years of hospice experience ranged from 1-24 years and the years of nursing experience ranged from 2-45 years. Over the course of their hospice careers, eight nurses had worked exclusively at one hospice, eight nurses had worked for two different hospices, three nurses had worked at three different hospices, and two nurses had worked at four different hospices. Eleven nurses had experience working at for-profit hospices while seven nurses had worked exclusively at non-profit hospices. At the time of the study, eighteen of the nurses worked at non-profit hospices and three nurses worked at for-profit hospices. The majority (17 nurses) worked at the same non-profit hospice while five nurses worked at other hospices (3 nurses at for-profit hospices and 2 nurses at non-profit hospices). Every nurse either currently worked for a hospice that had its own inpatient center (IPC) or had worked for a hospice with its own IPC. Eleven of the nurses had worked exclusively with adult hospice patients during their hospice careers, while nine of the nurses had experience with pediatric hospice patients. However, only one of the nurses identified herself as an exclusively pediatric hospice nurse. This particular nurse worked at a non-profit hospice that contracted with a different hospice for general inpatient level care.

Table: Sample Description

				Years Experience			Experience		
Participant	Age	Gender	Licensure	Nsg	Hospice	# of Hospices	For-Profit	Non-Profit	Current Hospice
1	58	F	RN	36	10	3	Y	Y	Non
2	70	F	RN	22	8	1	N	Y	Non
3	66	F	RN	45	10	2	N	Y	Non
4	59	F	RN	33	15	2	Y	Y	Non
5	57	F	LVN	30	10	1	Y	N	Non
6	59	F	RN	36	21	2	N	Y	Non
7	52	F	LVN	20	4	1	Y	N	Non
8	63	F	RN	41	13	1	Y	N	Non
9	63	M	RN	36	20	2	Y	Y	Non
10	53	F	RN	8	2	1	N	Y	Non
11	69	F	RN	48	13	2	Y	Y	For
12	48	F	LVN	9	7	2	Y	Y	Non
13	54	F	RN	28	5	2	Y	Y	Non
14	55	M	RN	33	13	4	Y	Y	Non
15	40	F	RN	11	6	3	Y	Y	Non
16	65	F	LVN	45	10	1	N	Y	Non
17	37	M	RN	2	1	1	Y	N	For
18	53	F	RN	25	24	4	Y	Y	Non
19	59	F	RN	36	13	1	N	Y	Non
20	57	F	RN	6	3	2	Y	Y	Non
21	40	F	RN	4	1	1	N	Y	Non
22	45	M	RN	23	19	3	Y	Y	For

Note. Nsg = Nursing;

Four of the nurses held licensed vocational nurse (LVN) licensure while 18 of the nurses held registered nurse (RN) licensure. Of the RNs, two were diploma prepared, seven were associate's prepared, six were bachelor's prepared, and two were master's prepared in nursing.

Study Setting

The setting of this project was San Antonio, TX (population 1.36 million). There are approximately 30 hospices in the San Antonio area employing nurses. These hospices include for-profit and non-profit hospices that provide the full range of hospice services (e.g., routine home care, general inpatient care, respite care, and continuous [crisis] care).

Procedures for Data Collection

One hospice gave permission (See Appendix A.) to interview their nurses. This hospice is a nonprofit hospice with its own IPC. The average daily census (ADC) of this hospice was 140-145 patients. The IPC is a 14-bed unit with an ADC of 8-10 patients. The hospice allowed the researcher to post a recruitment flyer (See Appendix B.) in the common areas at the hospice office and in the staff break room of the IPC. When a nurse contacted the researcher seeking more information regarding participation in the study, the researcher explained the purpose of the study and if the nurse was willing, asked to meet for an interview at a location away from the hospice at the nurse's convenience.

At the beginning of the interview, the researcher reviewed the purpose of the study, allowed the participant to ask questions, and obtained consent to move into the data collection portion of the interview. During the consent process, the researcher brought up the possibility of asking the participant to participate in a second interview for the purpose of member checking the theory. Additionally, permission to audio-record the interview was requested. All participants gave permission for the interview to be audio-recorded. If permission had not been obtained, then the researcher would have taken notes during the interview. The purpose of interviewing was to collect data that showed the relevant situational and social contexts while highlighting aspects of emergent categories. At the end of the interview, the researcher provided the participant with a recruitment flyer and encouraged the participant to identify any hospice nurse colleagues that they thought might be interested in the study and asked the participant to pass it along.

Observational field notes and memos supplemented participant-generated data. Based on the on-going analysis, the interview guide evolved as participants provided information regarding what is and is not important for how they identified and responded to their patients' suffering. Participant recruitment began after approval from the Institutional Review Board (IRB) was obtained (see Appendix C).

Instruments

Written consent was obtained from the participant at the beginning of the interview process (see Appendix D). A demographic collection sheet (see Appendix E) was used to collect demographic information about the participant after consent was obtained. An interview guide was used to ensure relevant topic areas are addressed during the interview (see Appendix F). The interviews ranged from 40 to 75 minutes. As previously discussed, the interview guide evolved with the input of participant data and on-going analysis, which is part of the grounded theory process.

Plan for Participant Protection

Prior to beginning data collection, the study proposal was submitted to the IRB at the University of Texas at Austin (UT Austin). As documentation of the researcher's knowledge of the roles and responsibilities of the key ethical principles and federal regulations to protect human participants throughout the study, the researcher completed the UT Austin's training affiliated with Collaborative Institutional Training Initiative (CITI).

The interview process might have been emotional to the participant. Exploring the participant's experiences of patient suffering might have uncovered or re-exposed the participant to issue(s) that the participant and researcher did not anticipate. Each participant received a phone call the next day to ensure that the participant was not experiencing emotional distress. No participant acknowledged any distress from the interview. Additionally, a community list of resources (See Appendix G.) was provided to the participant (with the consent form) in case the participant chose to seek additional help. The researcher is educated as an advanced practice nurse within adult health and palliative care; which includes hospice services. She has 15 years experience working in hospice and EOL related fields providing nursing services and supportive, emotional counseling to patients, families, and members of hospice interdisciplinary teams including nurses. Based on her clinical preparation and experience she is very adept at identifying individuals in emotional distress and referring these individuals to community resources.

The participant had the right to choose to participate or not to participate in the study. This is part of obtaining informed consent. Regardless of the perspective participant's choice, there should be no ramifications to their work environment. Therefore, the researcher asked the participants to choose an interview site away from their place of work.

Before initiating the interview, the participant was given a consent form for review that explained the purpose of the project, risks/benefits, and the participant's right to confidentiality. The participant was given an opportunity to have any questions answered. After this, if the participant was willing to proceed with an interview, then the participant was asked to sign the consent form and the researcher provided a copy of the consent form and the list of community resources to the participant.

Another area to address is the participant’s right to privacy. The interviews occurred in a private place appropriate for audio-recording. Participants’ names, locations, and other identifying information were removed from interview transcripts and a participant number used. After being sanitized of identifying information, interview transcripts were made available to the dissertation chairperson for review. Only the researcher knows the true identity of the participant. The research report does not identify any participants or settings and is written in such a way as to protect participants from being identified by individual readers.

Protecting the participant’s confidentiality with respect to data management will be discussed in the data management section.

Data Management

The interviews were transcribed by either the researcher or a transcription service (after reviewing their privacy agreement) into a Microsoft Office Word document. After the researcher verified the transcription’s accuracy by reading it while listening to the audio file, the audio file was deleted. All notes, transcripts, demographic sheets, and participant consent forms were kept in a locked file cabinet when not being analyzed. The participant consent forms were kept locked separately as a further safeguard. Additionally, the “soft” copies of the Word documents were kept on a password-protected computer. This information was only shared with the dissertation chairperson. Participant numbers are used instead of names to protect the nurses’ privacy when transcribing interview(s), writing the dissertation, and publishing the findings.

Data Analysis

Constant comparative analysis, a process that compares data with data, data with category, category with category, and category with concept were used to generate the abstract theory (Charmaz, 2006). The process began with an initial coding or categorizing of data segments into a meaning unit that helped define what was happening in the data. After initial coding of an interview transcript, a more focused coding was used to synthesize larger amounts of data generated from multiple participant interviews and memos. This focused coding used the most significant or frequent earlier codes and required decisions about which initial codes made the most analytic sense to completely categorize the data. Based on the analysis, axial coding and theoretical coding were used to bring data together into a coherent whole. Axial coding is a type of coding that treats a category as an axis that is used to delineate relationships and specify dimensions of the category in order to "see" the whole of the category (Charmaz, 2006). Theoretical coding is a type of coding that specifies how categories may relate to each other (Charmaz, 2006). Based on the comparative analysis, interview questions changed. Memos were completed after each of the coding sessions in order to explore ideas about the data and codes. As an analytic tool, memo writing captures ideas, comparisons, and connections about the data, codes, and emerging categories (Charmaz, 2006). The researcher's engagement is the intermediate step between data collection and drafting the developing theory that is uncovered using constant comparative analysis. As previously stated, data collection continued until saturation was achieved, meaning no new information was being uncovered. Trustworthiness was promoted by adhering to the methodology's design, reviewing raw data and analytic components with the dissertation chair, and also member checking with participants as needed. Member checking involved asking participants (of previous interviews and of on-going interviews) about their experiences with specific aspects of categories and if proposed relationships between categories made logical sense with what they observe and do.

Evaluative Criteria

Criteria for evaluating research vary depending on the nature of the research and its purpose. Charmaz (2006) offers the following criteria for evaluating constructionist grounded theory studies: credibility, originality, resonance, and usefulness. Credibility refers to the capacity for belief. Credibility concerns whether the range, number, and depth of data is sufficient to merit the theory's claims. Has the analysis and presentation of findings provided enough evidence for a reader to form an independent assessment and this assessment agrees with the researcher's claims? Originality refers to the freshness of insights. Does the analysis provide a new, conceptual rendering of the data? How does this theory challenge, extend, or refine current ideas or practices? Resonance refers to an enriching fullness of the studied phenomenon. Does the theory make sense to the participants or people who share the circumstance; does it portray the fullness of the experience? Usefulness refers to the theory's practical applicability. Does the analysis offer an interpretation that can be used in everyday life; does the work contribute to knowledge; and can it spark further research in the substantive area.

Within this study, the criteria of credibility, originality, resonance, and usefulness was initially evaluated by feedback obtained from member checking with study participants who were in the situation and by feedback from the dissertation committee. Each of these criteria will be addressed in the Chapter 5 of the dissertation. However, a more full evaluation of these criteria will only occur after dissemination of research findings that allows the findings to be scrutinized by a broader audience.

LIMITATIONS

Limitations of this study include issues related to the sample and also to the types of patients that these nurses care for. The sample comprises hospice nurses from the San Antonio, TX and surrounding area. This is a primarily Hispanic urban area in south Texas. The results may not be representative of other demographic areas; however, the results do provide insight and understanding of the phenomenon and a foundation for future research. These nurses chose to work with a dying population. Their skill set may be different (e.g., pain management, communication with sensitive topics) and their contextual work environment may facilitate identifying suffering that otherwise would go unnoticed. Additionally, the "typical" hospice patient may be different (e.g., age, diagnoses, personal belief system related to death, caregiver availability) than patients not attended to by hospice services. These patient differences could influence what the nurse identifies and how the nurse responds.

Chapter 4: Results

The purpose of this study was to generate a theory describing the process of how hospice nurses identify and respond to their patients' suffering. The specific aims for this study were: (1) to uncover what hospice nurses characterize as patient suffering, (2) to uncover the process hospice nurses use to respond to their patients who are suffering, and (3) to describe hospice nurses' personal coping strategies used when working with patients they perceive as suffering. Grounded theory methodology, as described by Charmaz (2006), was used to guide the design and data analysis. A purposive sample of 22 hospice nurses from the San Antonio, TX area was recruited to participate in one-to-one interviews. Constant comparative analysis was used to analyze the transcripts, field notes, and memos. Based on the analyses, axial coding and theoretical coding were used to specify how the categories related to each other as a whole in an iterative process to uncover the theory.

This chapter presents the theory as outlined in Figure 2 (See Figure 2). In this study, participants were only able to identify and respond to their patients' suffering within the context of the nurse-patient relationship. Regardless of any specific nursing task, the participants always worked to cultivate the nurse-patient relationship as a special type of trusting relationship. From the participant's perspective, the nurse-patient relationship had specific phases: preparation phase, establishment phase, cultivation phase, maintenance phase, and the letting go phase. Cultivating this trusting relationship enabled the participants to focus on accomplishing their (the nurses') goals of optimizing the patient's QOL and orchestrating a peaceful death. Over the course of time, through this relational context, the participants responded to their patients' suffering using a sequential process of observation, issue assessment, suffering, and intervention.

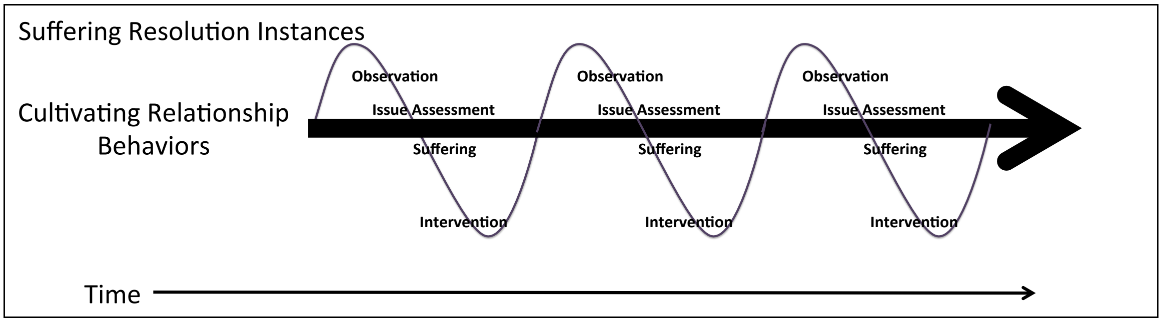


Figure 2: Suffering Resolution in the Context of Relationship

In order to provide the background for how the participants characterize and respond to their patients' suffering, the role of trusting relationships, the nurses' goals, and an elaboration of how the study participants viewed the nurse-patient relationship will be provided. From this vantage point, Aim 1 will be addressed in the Hospice Nurses Characterization of Patient Suffering section. Aim 2, the theory, will be presented in the Process Hospice Nurses Use to respond to Suffering Patients Section. And finally, Aim 3 will be addressed in the Hospice Nurses' Coping Strategies section. For protection of the participants' identities, each individual is identified by participant number only.

THE ROLE OF TRUSTING RELATIONSHIPS

In clinical practice, hospice nurses have two primary goals for all of their patients: to optimize the patient's QOL and to orchestrate a peaceful death for the patient. The study participants all concurred that in order to understand what the patient considers important for QOL and to elicit concerns the patient has regarding one's death, they had to develop a trusting relationship with the patient and family. It was within the context of this relationship that participants could then identify and respond to the patient's suffering. As such, the hospice nurse-patient relationship was a pre-requisite and a co-requisite for identifying patient suffering.

The nurse-patient relationship provided the working context for all interactions. The study participants indicated that the existence of the relationship created responsibilities and accompanying expectations for each party. The patient's (and family's) responsibilities include providing honest answers, communicating information to the nurse in a timely manner, and adhering to medication/treatment schedules. The hospice nurse responsibilities include providing oversight of the relationship with a focus on gaining and maintaining the patient's (and family's) trust. The relational context determined which resources the nurse could effectively use to build trust and/or resolve identified issues. Within this relationship, the participants often viewed themselves as trusted "advisors" providing options to their patients and families. For instance Participant 6 stated:

> And then reality sets in. It's really not about me. Now, I have an obligation as a nurse to instruct them, to give them the best information I can based on whatever the latest research is, what the doctor's instructions are. All these things, that's my job. After that, it's out of my hands. My patients are going to make their decisions based on their own philosophical, you know, their own family realities….My obligation is to give them the best information and to support them the best way I can.

Similarly, Participant 8 reflecting on the importance of being trusted, stated:

> I think trust for the patient is essential from the nurse. But also the family. Because you're not there all the time. So, I think the patient has to trust if the family's going to do the right thing then the family has to trust that I've told them the right thing. And so there's a lot of trust….I would find it difficult to be near death and not believe that whoever is taking care of me was going to do the right thing for me…..From the patient's perspective, it's critical.

The participants invested their time, talent, and energies into cultivating a trusting relationship with their patients for the purpose of guiding the patient to a (hopefully) peaceful death. As advisors, they brought a certain set of knowledge, skills, and abilities to the relationship. Just as a financial advisor is bounded by the terms of a specific fiduciary relationship with one’s clients, the participants were also bounded by a fiduciary relationship created by the nurse-patient relationship. A fiduciary relationship can be described as one in which one party (the patient) places one’s trust in the other party (the nurse) to act in one’s (the patient’s) best interest. This fiduciary relationship implies an obligation to act in the patient’s best interests. This is analogous to the more commonly used healthcare ethical principle of beneficence. As an ethical principle, beneficence prescribes an obligation for the nurse to act in the patient’s best interests. Within the fiduciary relationship, the participants acted in a professional role, which entailed specific obligations to patients and this affects how the nurse’s character and actions are evaluated. But, unlike the financial planners’ fiduciary relationship with its fee-for-service contract language that both parties are aware of, the hospice nurse-patient fiduciary relationship was a caring relationship based on the emotional trust the patient placed in the nurse and the very personal, relational-engagement between the nurse and patient.

Indeed, the participants’ way of being (e.g., openness, respectful attitude) coupled with specific behaviors (e.g., truth-telling, touch, being present) were the resources used to broach difficult topics throughout the relationship’s course. As advisors, the participants viewed themselves as invested in these relationships, often times defining short-term success as a patient becoming more self-disclosing and truthful about occurrences happening around them between the nurse visits. The openness and enjoyment of these visits gave the participant a better opportunity to orchestrate a peaceful death for the patient. However, experiencing multiple challenging visits increased the participant’s concern that the patient’s death might be problematic and a difficult experience for the family. A patient dying peacefully was one of the most important markers of the relationship’s long-term success to the participant.

Just as a financial planner conducts conversations around a client's financial goals within the context of their current and future financial dreams, the hospice nurse conducts conversations around a patient-family EOL goals within the context of the current disease state, natural course of the disease process, and dying process while taking the current situational environment (e.g., house, family relationships, symptom experience, emotional reserve) into consideration. A financial client's various goals may compete with each other regarding whether to maximize dollars now for a short-term goal or to build a steady stream of income for a long-term future. Similarly, the hospice patient's goals may compete with their family's goals regarding symptom distress/relief and participating in life-closure tasks (e.g., saying goodbyes). Just as a financial planner considers the risks and benefits of various investment strategies in relation to the client's risk tolerance and investment horizons, the hospice nurse considers the risks and benefits of various care strategies in relation to the patient's current QOL and survival horizon. While the financial planner guides the client towards choosing specific types of financial instruments (e.g., stocks, bonds) in relation to the benefit of gaining or the risk of losing money, the hospice nurse guides the patient and family towards choosing specific types of interventions (e.g., medications, use of medical equipment, engaging different conversations) in relation to the risk and benefit to the patient's QOL. The participants' interviews revealed that the complexities of the hospice nurse-patient relationship were multifaceted and could be characterized by the hospice nurse goals and relationship phases, including preparation, establishment, cultivation, maintenance, and letting go. The following includes an explanation of each with illustrative quotes.

Hospice Nurse Goals

The study participants defined success as achieving the patient and family's goals. Eventually, this centered on orchestrating a peaceful death for the patient and a "good" death experience for the family. The participants viewed their responsibility as identifying goals, anticipating potential problems, and developing various care strategies to optimize the patient's QOL, while mitigating any negative developments within the specific context of the patient's family situation. To this end, they had multiple conversations with the patient and with family members concerning goal setting with ongoing QOL and finishing one's earthly business given highest priority. Often, there were competing goals that were complex with varying degrees of realistic probability. Within their advisor role, the participants shepherded the patient's and family member's mental and emotional resources while they did the daily patient-care work. For instance, one nurse (Participant 9) reflected on a situation where the wife of a patient with dementia was having difficulty reducing the amount of tube feedings she wanted her husband (the patient) to receive. The patient was consistently aspirating the feedings, vomiting often, and having recurrent episodes of pneumonia. The nurse wanted the wife to decrease the tube feedings while the wife wanted to continue tube feedings because she felt obligated by her love to the patient. The nurse stated:

> You have to let people wallow in the mud. They've got to taste the mud and eat the mud, and when they're ready, they'll ask you for help. And when they ask you for help, then show them which road, but you don't show them what the road to take is until they are ready or ask you which direction to go. They have to make the choices. Now, it's not your house, it's not your home, it's not your life. It's theirs. They have to be in charge of the choices and the decision. You can only give examples, or show, or teach, but that's as far as you can go.

Preparation Phase

Nurses self-select into the hospice environment. All hospices work from the same basic mission statement—to make the patient's last days on earth the best possible days that they can be. The goal for this phase is for the nurse to be prepared to provide the specific care needed by the particular patient and family. As such, the study participants prepared for a patient relationship by finding information specific to the particular patient. This included finding out background (i.e., medical history, housing, family relationships) through reviewing a patient's clinical records and/or receiving report from a prior nurse, anticipating potential needs, and mentally preparing themselves to enter the new relationship. Participant 3, an admissions nurse, explained:

> When we get a referral, we'll get clinical information and I always go ahead and write a summary so I know what's going on but when I walk in there, I don't tell them right away that I know what's going on. I need to know if they understand what's going on and where they're at….I think listening with your heart is where the caring, where the empathy…it's just caring. They know that you're there for them, that you're going to help them, and that they need you and that they're accepting your help, and that's a lot of responsibility I feel.

Additionally, Participant 13 clarified, that in addition to having clinical and demographic information about a patient, she needed to really find out about her patient—the patient's hopes, dreams, concerns, fears, relationships, and needs. She related:

> I try to clear out my stuff. I do not go in to start to take control. I go in and I first have to find out who are they? Where are they? Where do they want me in their life? And what do they expect from me, the nurse?

While this preparation was initially done before the participant first met the patient/family, it was repeatedly done to "update" the participant between nursing visits for home-hospice nurses and at the beginning of the shift at the hospice in-patient center. This prepared the participant to re-enter the patient's particular world.

Establishment Phase

These participants were very aware of how they presented themselves to their patients/families. The most important goal was to gain the patient's trust and then to foster the growth of this trust. The mechanics of a patient encounter provided the framework. During the initial encounter the participant began with introductions, stating their roles as the nurse, maybe describing a little about the hospice service or their personal nursing background, but, really focusing on communicating that they cared about this person and their family. Participant 21 shared: "You have to show you care. These are the last days, it could be the hours, for the patient and the family. And they need to know that you're there to support them."

At the beginning of the hospice nurse-patient relationship, the nursing task was to assess the patient's physical well-being and get to know the patient's circumstances (living arrangements, who is who in the family, what's important to the patient, what's important to the family, what the immediate needs are). Participants used this time to build connection with the patient (often referred to as "building rapport") and finding something to "bond" with the patient over (sometimes this occurred with a family member). This bonding united the participant with the patient establishing the nurse's loyalty and commitment to the patient. The participants' main indicator for success was their personal sense regarding whether or not the patient/family trusted them and/or liked them. Participants who sensed the patient not trusting them or not liking them personally acknowledged they were (probably) the wrong nurse for that patient. Sometimes they could make this determination individually, but sometimes, this determination came after discussing the matter with their interdisciplinary team (IDT). Participant 12 shared:

> Sometimes that happens with nurses. You're just the wrong nurse. And so if you start feeling like, or the family calls and complains, it's the wrong nurse. You've

> just got to change the nursing [provider]… In the IDT, it became recognizable that the patient needed…someone else.

Cultivation Phase

In order for the promise of this relationship to grow, the participants then started setting and managing the expectations of the patient and family. This was tricky. The participants made promises about their own behavior and for the behavior of others from their hospices; which the participants knew full well that they had no control over. Nonetheless, they indicated that they had to trust that one's team members would follow through. Participant 4 pointed out:

> I have found that that it doesn't take a real long time, usually, to start getting that trust laid down because if I say I am going to do something, I'm going to do it. You are going to see results. And you will see that that is going to be my pattern. If I tell you I can't do it, you're going to know I can't do it. If I tell you that I'm going to go see or get the information, then I do that. It just takes a couple of incidences of me saying what I'm going to do and doing it. And it becomes what they expect it to be. You know?...When I order medical equipment, I'm not the one sending it out there. But, I'm the one that called for it…so, its my responsibility to see that it's taken care of.

Over time, the participant's success with managing patient/family expectations determined the soundness of the nurse-patient relationship and if it would continue to grow. During this time, the participants focused on maximizing patient's QOL, being present focused, acknowledging one's limits, and providing an emotionally safe place for the patient. Indicators for success were when the patient and family began self-disclosing information and consistently trying the interventions suggested by the nurse.

Maintenance Phase

As the relationship matured, the participants' connection with the patient and family provided the relational context for broaching more difficult conversations and engaging in practical preparations for the patient's death experience. These conversations required the nurse to be sensitive to the patient's (and family's) psyche and emotional make-up in order to successfully provide them with needed information while supporting the individual working through their emotions. As previously mentioned, indicators for success were when the patient and family (1) self-disclosed issues and (2) reliably took the nurse's advice. Participant 14 pointed out:

> Initially, most patients are not going to be self-divulging. But as you build rapport with the patient, they become more free. And then you can sense certain changes in behavior, or just by asking them….The objective is for them to become more self-reporting….so they either have to like you or feel confident with you based on your knowledge.

Or as Participant 17 explained:

> I just give people an honest opinion, give examples the best I can of how it's helped other people….I just build a good rapport with families so they trust me and what I'm doing. And they'll tell me things that are happening. A lot of reasons. You're dealing with their loved ones and they need to trust what your doing…and the information you're giving them is helpful to them.

This enabled the nurse to broach some of the more emotionally charged issues the patient/family may have. Participant 4 related:

> When patients seem not in the right place for where they are, not that there seems to be anything wrong. You've already taken care of what you know to be wrong, you know? You've already got things addressed. You've got meds on board. They're taking the meds and they're saying they get relief…But, you know something's not right. I know I need to open a conversation about what else is going on….They need to talk about these things. And you can't do that if you don't have a basis of trust with the patient….So, you've got to get that trust and maintain that trust, and honor that trust.

Letting Go Phase

The end of the relationship was signaled by the patient's death (most often), transferring care to another nurse, or by the individual leaving the hospice program (revocation to seek alternative treatment, moving, or becoming stronger and no longer having a terminal prognosis). By this point, the participants had invested time, professional talents, and emotional energy toward maintaining and growing the relationship. While the death itself ended the relationship with the patient, participants' fidelity to the relationship obligated them to provide comfort to the patient's family members during the immediate bereavement period and to ensure the family members would be cared for during their time of bereavement.

While hospice nurses working in IPC and home-based (field) hospice nurses provided similar examples and descriptions of the importance of cultivating and maintaining trusting relationships, the main difference between the two settings centered on the limited time span the patient was in the IPC and the nurse's shifts. While a field nurse may have spent an hour with a patient during a home visit, an IPC nurse spent a few minutes at a time over the course of an 8 to 12 hour shift. This contributed to the IPC nurses' feeling that they often did not know their patients as well as the field nurses knew their patients. However, the IPC nurses felt that their relationships were more intense compared to the field nurses because the patients came to them during a pain/symptom crisis or because the patient was actively dying and could not be managed in the home setting. Participant 12 reflected on building relationships with patients coming directly from the hospitals to an IPC where they were expected to die within a few days:

> You have to be very quick and tell them the way it is, really quick, and help them grasp an understanding of it. Sometimes they [the family] come from the hospital barely knowing the patient is going to die. Its like something sudden and they don't have time to prepare….They [the patient] may have been sick awhile, but they don't know they're going to die. And so as soon as you get them, you have to build a relationship with that patient immediately. But, sometimes the patient is unresponsive. So, you can't even build with that patient. You have to go straight for the family and build some kind of rapport with them…You see all these family dynamics that are going on with the family, there's feuding between brothers and sisters...so there's a lot of tension, and when you walk into the room

> you feel it. And then, you have to get it under control, then you see the patient usually will get more under control, and you see less anxiety [within the family].

Similarly, Participant 9 related his feelings about working in the IPC compared to his time working as a hospice case manager in the home setting:

> [In the IPC] Ours is mostly shoot and run. Most of them come for symptom control, so you focus on getting the symptoms under control. And you don't have the relationship already developed that maybe the home nurse, in the home setting would have. If you're green and you're new, they don't know you, you don't know them, so you don't know where they're at, where they have been, or where they are going. And so, it's like starting at the beginning with them….It's more difficult, you can't go in and start to—you can't start those discussions about what are your beliefs or values, you know, you have to build to those discussions. There has to be a pretty good trust pattern already established to get pretty deep in the psychosocial questions.

In summary, the study participants emphasized the importance of the nurse-patient relationship as a pre-requisite and a co-requisite for identifying patient suffering. Their observations revealed a complex, multiphasic process that required careful and ongoing attention in order to build and maintain a trust that would allow them to address their patients' suffering.

HOSPICE NURSES CHARACTERIZATION OF PATIENT SUFFERING

This section addresses the first study aim, which is uncovering what hospice nurses characterize as patient suffering. Participants characterized different aspects of their patients' suffering in terms of pain, emotional suffering, a family affair, loss of identity, and frequently with the phrase: "suffering is suffering." Participants did not go into patients' homes with the idea that a patient might be suffering. They went into the home with the idea (or goal) of wanting the patient to be as comfortable as possible. Suffering prevents patient comfort and can interfere with the patient's relationships. This is the primary reason why suffering should be addressed.

Usually, a component of physical suffering (e.g., pain or anxiety) was observed first. However, this physical symptom experience was not considered "suffering" until the usual measures of education and medication titration had been tried and failed. When these usual measures failed to resolve the symptom, the participant conducted a more thorough issue assessment while continuing to increase medication dosages. At this point, the patient might have had medication doses and needs that had escalated far beyond normal doses and the patient still required more medication while achieving only minimal relief. When a participant considered the amount of medication that the patient was receiving with its minimal symptom relief, this triggered the nurse to consider additional evaluation of disease progression, patient-family dynamics, patient history, non-use of medication (either patient choosing to not take it or medication being diverted), and to search for other factors that may be influencing the situation. Within this context, patient suffering was identified as "suffering" and then interventions aimed at relieving the suffering were used (see Figure 2).

Pain

Every participant in this study gave "pain" as the first descriptive characteristic of suffering. Using the word "pain" as their starting point, they then qualified it by describing an unrelenting physical aspect—unrelieved physical pain, pain without end, uncontrolled pain, patient nonfunctional due to pain, miserable pain. For instance, when Participant 1 began considering what suffering was, she immediately shared:

> I have a patient right now who is suffering because she fell and she can't get relief from her pain and to me that's suffering. Either they can't do what they used to do, what they always do or they're in pain and they don't see life without pain.

She went on to describe this patient's sense of being defeated and not being able to return to her previous level of functioning. For Participant 1, this came across as her patient wanting to give up on life and observing increased signs of fatigue and hearing statements of "being too tired to take it" anymore.

Many participants gave a text-book type definition of pain stating: "Pain is whatever the patient says it is." They would then go on to say that pain could be physical, emotional, or spiritual. For example, Participant 20 explained:

> One textbook answer, because it's what the patient says it is…the physical side of pain is. If the patient tells you it's a six of ten, it's a six of ten, because you can't feel what they're feeling so you let them tell you. The other side of it is there's spiritual pain and there's emotional pain. And then there's flat out psychological pain that is the result of things going on in their own head that aren't necessarily emotional, but are psychologically related.

Interestingly, while many of the nurses provided multiple examples of physical pain and emotional pain, examples of spiritual pain were much harder for them to recall. The exception to this was when they described episodes of terminal restlessness. Terminal restlessness is when a patient is in an active dying process and appears uncomfortable, characterized by a tense face and posture, frequent (non-purposeful) movements, stuporous level of consciousness, and occasionally crying out. When this state was not easily relieved by an appropriate dose of pain and/or antianxiety medication and continued for more than a couple of hours, the participants identified it as terminal restlessness and attributed it to a spiritual suffering due to "unfinished business." For example, Participant 6 shared this patient's story:

> We had this one patient that we couldn't, we couldn't figure out for the longest time why she was still alive. She had no blood pressure. We literally, even a palpable one, we couldn't get a blood pressure on her. She was that way for days. No urine output. She looked like she had this pained look on her face. She was on three drips, Dilaudid, Versed, and something else, the triple cocktail, you know? It was like "Why is she here? Why is she still here?" Well, her son made a comment, in her last two days. She used to, she was into voodoo. And we think that maybe she's afraid to die. She's afraid of what's going to happen to her because of what she did….Knowing that at least gave us some insight into what

> had been holding her there, you know? We could get the chaplain in, get her some spiritual support…Because she had looked like she, she looked like she had sheer terror on her face for that last week. It was like, it didn't matter how much [medication] she was on, like enough to kill a herd of elephants….We wanted to help her, we liked her, we liked her family. The family was exhausted. Why is she still here? What can we do to make her be able to let go?

Pain was the symptom most associated with suffering and, at first, it seemed that just the presence of pain indicated suffering to the nurses. However, it became clear, that this was the symptom they most assessed and pain could be present without suffering. An example of this is when nurses would relate achievable pain relief after proper medication administration. Participant 22 explained:

> Pain is relative; there are different levels of pain. People tolerate pain differently. I had a patient, she said "I'm in pain all the time. But when you get me to a 12, that's too much pain." So, what would end up happening is we would get her to a five. And once she got to a five or six, she was able to tolerate that. So that's when it wouldn't be suffering because its something that they live with, something that they have. And so, they understand that.

Similarly, Participant 11 shared a story about a gentleman with two young sons aged 10 years and 12 years who would not take any pain medications including acetaminophen because he wanted to be as engaged as possible in his sons' lives for as long as possible. She shared:

> I had to respect his decisions on that. I couldn't push medicines. I let him know that we had things available and I let him know when he was ready, that we would get him pain medicines. And he started with mild stuff, Extra Strength Tylenol. And up until the last three weeks of his life he would not take any of the heavier pain medicine until it got so bad he could not get up. And then he would allow pain medicine…but, even then he would back off on it when it came time for them to get home from school. And he had to have that control….That was his quality of life, putting up with that pain to not miss one minute with those boys. He enjoyed them. If I had tried to take that away, he never would have trusted me. I had to respect his quality and understand what his quality of life consisted of before I could encourage him one way or the other.

However, when pain relief was not easily achieved or if there was a sense of "unease" or "discomfort" about the patient, then the participants investigated this much more thoroughly and this was where additional aspects of suffering became apparent to them. During these times, the participants linked the pain to additional physical manifestations and verbal disclosures by the patient. For instance, the participants described declining physical function, anxiety, looking depressed or "down," overarching fatigue, and hearing patients verbalize fears, regrets, aloneness, and a general hopelessness about the present situation. Participant 20 shared:

> I had a little lady who told me once that she wasn't having any pain. And I watched her and she did this (makes a hand gesture) constantly, the whole time I was there. Now, it wasn't pill rolling. It was her defense mechanism to keep her from telling me what was really going on I think. And finally I took her hands one day and I just held them. And she said, "Why'd you do that?" And I said, "I want you to tell me why you're doing that." And she said, "Oh honey, there's just so many things going on. And I just don't know what to do about them." And her whole face scrunched up, you could see the stress. That's suffering. That's something we needed to deal with.

In addition to pain, nurses identified other symptom experiences (e.g., dyspnea, nausea/vomiting, anxiety) as potential signs of suffering indicating that further investigation was needed. The unifying thread for when to consider these symptoms (including pain) as suffering was that they were not easily relieved by appropriate medication dosages. After ensuring the medications were at effective doses and the patient was taking the medications, then the participants considered the situational context of the patient. This included the patient's physical, mental, and emotional condition, the disease progression, and family dynamics, including role shifts/losses.

Emotional Suffering

For the study participants, suffering that was not predicated on a physical symptom seemed to fall within a broader category of "emotional suffering" and included emotional and relational components. Frequently, participants talked about patient role losses (e.g., matriarch, bread-winner), the patient's impending death, patient aloneness (especially when the patient did not have family support), patient reported feelings of guilt and regret, patient not able to sleep, patient burdened by worries, hearing patient expressions of grief, patient frequently needing reassurance, patient not being able to tolerate any change, patient "acting out" in ways not consistent with their usual personality, and chaotic home environment. For example, Participant 19 related the story of a 48-year-old woman, married with children who were 21 and 13 years old:

> And you could see that she didn't want to let go because of the family and all that. And towards the end, it was mainly the husband and the older daughter that I could see were having a real hard time with her. And she was too. It was very hard for her to let go. She held on and on and on. But, I could tell there were some problems there. But not to the extreme where they were in denial. They knew they had to let go, but they wouldn't open up to let it go. You understand what I mean? Well, the patient never really opened up. The husband did. And I think that was one of the things, because she was afraid, she didn't want to let go because of leaving her husband and children….it was hard for them to believe this was going to happen, but the communication got better…he said "She's tired and we don't want to see her suffer anymore. And we know that the Lord's going to take her. We're ready. I want her to go because I cannot take it, seeing her like this anymore."

Often times, participants identified aspects of spiritual suffering, such as meanings associated with losses or changes in roles, when they discussed emotional suffering. As previously stated, examples of spiritual pain were difficult for the participants to identify with the exception of terminal restlessness. From the participants' perspective, terminal restlessness was a type of spiritual suffering due to "unfinished business."

Family Affair

Interestingly, the participants also identified suffering as a family affair. For them, suffering not only occurred within an individual but also encompassed the entire family unit, with each family member experiencing their own personal suffering and a communal suffering. Participants began talking about “family suffering” when they discussed “family dysfunction” and “caregiver breakdown.” They often observed chaotic homes, noticed tension between family members, saw open secrets not being acknowledged between family members, listened to family members not asking each other important questions, and not answering important questions when they were asked. Frequently, at the end of their visits, the participants would be followed to their cars or taken aside as various individuals (patients and/or family members) wanted private opportunities to share regrets, feelings of guilt, anger, and just generally being fearful of what was happening. Within the IPC environment, the nurses would be sought out in the hallways, at the nurse’s station, or called back into the patient’s room after family members had left. Participant 22 shared the example of a family’s suffering in relation to the burden and uncertainty involved with providing care to a dying patient.

> A family caring for a patient, they are there 24 hours a day, seven days a week. The illustration I use is it’s like having your firstborn. When your child moves as a baby in the crib, the mom pops up to check on the child. Now transition that to an older person, an adult. Every time that person moves, you wake up to make sure they’re okay. Now, you’re feeding them. Now you’re giving them the medications and you have the uncertainty. “Am I killing my loved one? Or, am I helping my loved one?” And then you have the outside pressures of the family members that are not caring for your loved ones every single day pop in and out. So it’s a lot of internal struggles they have. It’s an emotional struggle for the family members. And the patient feels that. You will literally see a patient become more tense because they know even if they’re comatose that a family member is being subjected to different type of stressors [from other family members].

Relatedly, Participant 15 shared:

> The family is just sorrowful. There's nothing that their seeing more than that they're going to die, you know?...I think the suffering is individualized and family-wide. Because with adults, when they're dying, you get—I have experienced a lot of "I wish I would have," "I wish I could have done," "I hope something will be better after I go." A lot of "I wishes" And when the person is in that mode of feeling guilt, per se, the whole family is feeling it. They have this unspoken…not peaceful, with them, you know?

Identity

An incredibly interesting and poignant aspect of suffering that some of the participants discussed was their realization that their patients were suffering because they had lost their self-identity. Participant 20 succinctly summarized it with these words, "and when someone has been given a terminal diagnosis, there's the pain of a loss that's impending. And it's the greatest loss any of us will ever suffer because it's the loss of ourselves." Similarly, Participant 22 reflecting about how he considered the patient's perspective of a situation explained:

> I've been independent all this time, and now I'm not. I'm about to transition. That's a very difficult identity. That's a very difficult reality to set in. "I'm about to die." By identity, I mean you are an independent person and all of a sudden, you can't do for yourself, you can't pick up a cup of water to drink. You can't take a breath without being short of breath. That's very difficult. That's the identity of who you were and who you are now. What your limitations are basically. And, then on top of that, when you look at it, and say to yourself, "Who am I or where am I in this process?" …And they change everyday, and their families have to adjust to it.

While considering a suffering situation over time, Participant 17 stated:

> It [suffering] affects everything about them. And some people lose their self-identity with that. They lose the dignity they had before that….They lose who they were. They forget who they were. They forget the good person they were, what they did in life. All they think about, you know, is that they're dying and they don't remember the person that they were.

Suffering is Suffering

When queried about the role of age, gender, race, and cultures within suffering, the participants reported that "suffering was suffering" and these attributes did not matter. When probed, they often admitted that "stoic" patients were the most difficult to assess. It seemed that stoicism prevented the individual from disclosing what was going on, and if something was occurring, the extent of the issue. Almost always, the participants expressed some uncertainty regarding stoic individuals and their suffering. Sometimes, age would make a difference in what issues the participants expected individuals to verbalize; but always, the participants stated that because they worked really hard to know and relate to the patient (and family), these attributes (i.e., age, gender, race, culture) were of secondary importance. The exception was if the participant could not for some reason relationally connect to the patient and, in these instances, the nurse would rotate off the case. In a reflective moment, Participant 11 shared:

> [People] want to be liked. They want to be accepted for who they are…they all have different experience backgrounds, different things that are, have happened to them, different things that are important to them. And you don't always know. And you may step on a toe without even knowing it…I have been in nursing long enough to know, I am not the be all, end all for every patient. And there are times when someone has asked for a different nurse. Somebody goes in on-call and they just bond with them. I don't take it personally because I have gone to people that somebody else didn't like. And I think that other person's a great nurse. But they bonded with me, something about me…I don't know why one likes me more than someone else, or why they don't. And I can't let that make my career miserable, you know, that I can't be perfect for everybody.

Pediatric hospice patients and their families were especially concerning to the participants. Participant 8 identified a special sympathy she felt for the parents of dying children. In this sympathy she realized the parents were losing their dreams of whom the child would grow to be. She reflected:

> And I feel sorry for the mother for the child hasn't lived his life. I guess that's, I don't know, it seems to be a sad thing because they don't, they haven't had the opportunity to play soccer or to go to college, or to get married. So my sympathy is more for the parents and the grandparents than what the child is missing. Because in my spiritual way of thinking, the child is not missing anything. He's going to be with God. And he's not sitting there thinking, "Dang, I never got to play soccer." The child, himself, isn't missing it, you know?

One nurse, Participant 15 related that in her experience, children were more spiritually connected with themselves and not afraid. Children seemed to sense that they were dying. And while the dying, itself, was not scary, the concern and worry they had for their parents and family could be overwhelming. She shared:

> The kids don't have so much "I wish I would have." They're like okay with right now. The worry is for their mom and dad….seven-year-old boy, and he told me, "Miss NAME, I'm ready to die but mommy isn't ready for me to go yet. Will you tell her?" And I'm an advocate for my patient and I was like, "Oh God, how am I going to tell her?" And he goes, "Please." He had tears in his eyes. "Please, please, please tell her." And I said, "Okay, I will."

Participant 15 shared the conversation she subsequently had with the child's mother. Over the course of the next two days, the nurse and the mother engaged in frequent, emotional conversations. After one of these conversations, the mother told her son that he could go. The child then slipped into unconsciousness and died eight hours later.

Likewise, Participant 21 shared her experiences of children "just knowing" that they were ill and would die. Suffering for the children was the emotional pain of leaving one's family behind, of disappointing them by not remaining alive. She reflected:

> Sometimes I wonder if the kids who hang on for so long, you know, a kid that doesn't eat for 45 days, who can't eat and is still alive, skin and bones, literally. I think of that as suffering, the emotional pain….I definitely see that [suffering] in the child and family. I think they feel it differently, maybe….About parents, their emotional involvement here is, I'm not doing enough for my baby or my child. I'm going to be losing my only daughter. You know? In their minds they've made plans for their daughter to be wed someday and for stuff like that. These are all

> emotional pains they're going through. A child might be afraid of not being there for their little brother like they once were or I'm not going to be here for Mommy and Daddy…A child cannot understand emotionally what a mother goes through. And a mother, even though she's been a child herself, cannot put themselves in exactly the same position the child is going through.

In summary, hospice nurses identified suffering in the context of relationship. Participants identified pain as the first characteristic of suffering because it is what they assessed for most often. However, any physical symptom not relieved by the usual doses of medication(s) was further investigated. For participants, emotional suffering included role losses, considerations of the patient's impending death, patient aloneness, and feelings of guilt or regret. Interestingly, suffering was also considered a family affair and could involve the loss of self-identity. While the participants would use the phrase "suffering is suffering," they often had doubts about their ability to identify the suffering of individuals they deemed "stoic" or patients they had difficulty connecting with.

THE PROCESS HOSPICE NURSES USE TO RESPOND TO SUFFERING PATIENTS

As previously stated, the hospice nurse-patient relationship was a pre-requisite and a co-requisite for identifying patient suffering. Throughout the course of the nurse-patient relationship, the study participants sought to understand what QOL was for a patient and to address concerns a patient and family might have regarding the patient's impending death. Through the cultivation of the nurse-patient relationship, the participants gained insight into the psychosocial and existential aspects of the patient's and family's psyches. Within this relational context, the participants used a four-phase process: observation, issue assessment, suffering, and intervention to respond to their patient's suffering (see Figure 2). The following includes an explanation of each with illustrative quotes.

Observation

Hospice nurses observe their patients and their patients' families. In addition to noticing the expected signs and symptoms that accompany various disease processes, the participants specifically looked for indicators of physical decline, medication side effects, emotional vulnerability, and indicators of how well the patient was being cared for when the nurse was not at the patient's residence. Even though the talk was about a patient—what the patient was experiencing or doing—the participant relied on the special nature of the relationship in order to intervene and influence decision-making (by the patient, by the family, and the healthcare team). By relying on the relationship, the participant bypassed becoming attached to specific outcomes that might later impair the relationship. Every interaction the participant had with a patient and family was geared towards either increasing the trust the patient/family had in the nurse or identifying an actual or potential problem.

This observation required the participant to spend time cultivating the relationship with the patient/family. Dependent on the phase of the relationship, certain behaviors were more salient than others. For instance, a nurse preparing to meet a patient is more concerned about having a sound knowledge of pain and symptom management rather than opening a conversation regarding whether the patient would prefer to die in the family's living room or in an IPC.

The nurse's personal investment in the relationship came from the nurse's willingness to personally be with the patient, modeling vulnerability through personal self-disclosure that invited the patient to accept one's self too. The participant invested in the relationship through the provision of care, which was manifested in the participant's attitude, words, and interventions directed toward the patient and family. The participant recognized that caring for the patient included caring for the patient's family. Participant

3 related an experience about meeting a non-verbal, minimally alert dementia patient and his family:

> I think it's important to show the family that you are genuine by going to the patient, taking their hand, and saying, "How are you today, Mr. NAME?" They'll (family members) look at you and it's okay. He (the patient) sees I'm here and I want him to know I'm here even though he may not understand, he absorbs or feels. It's important to let the family know that you're not just there for the mechanics….I want the family to know that together, we're going to take care of you (the patient)….We got to take care of him and indirectly, we take care of the family also because if we're able to help the patient be comfortable, the family's going to relax. And that's the other thing that we do, release the tension in the home and the stress.

Participants used an accepting attitude and gentle probes to explore potentially volatile emotions and issues that the patient and family may be hesitant to bring up. The purpose of these discussions were to provide the nurse with information regarding how the family unit currently worked, the potential effects of the patient's eventual death, and an understanding of what was currently most important to them. With this information, participants were able to offer emotional support, anticipate what potential issues might occur, and provide relevant information (teaching) to the patient/family. Participant 14 shared:

> It's giving the family feedback, giving them things they can look at so they can analyze the situation. An example is when I go into the home and the patient is dying. I ask the family, "Do you want that bedroom to be the place your dad dies?" And they say "I haven't thought about it." Well. That's why I'm mentioning it. When they're in crisis of losing their loved one, they can't think of everything. So, it's our job, based on our experiences to bring these things to light so that they can think about it and choose…And then we can try as the patient declines to rearrange things if needed.

Issue Assessment

An issue is any concern or problem that interfered (or could potentially interfere) with the patient's QOL. The issue could be physical (e.g., pain, dyspnea, decline in patient function), emotional (e.g., depression, anxiety, unrestrained worry), psychosocial (e.g., family dysfunction, relationship estrangement, living arrangements), or existential (e.g., unfinished business, legacy work, afterlife) in nature. Issues reside in the larger context of relationship and are addressed as they are identified because they interfere with achieving patient/family goals. When an issue interfered with goal attainment, there was either friction in the nurse-patient relationship or within a patient-family member relationship (e.g., between patient and spouse). The nature and character of issues changed over the course of time (e.g., disease progression, active dying) and over the course of the relationship (e.g., establishing, mature). In general, when the relationship was "new" or in the establishment phase, issues tended to have a more physical focus such as pain relief. As the relationship matured and the trust level from the patient/family in the nurse increased, more emotionally charged issues were brought up (e.g., relational discord, existential angst).

As a participant became aware of an issue, the participant did a more focused assessment trying to understand the underlying problem(s). At first, the "usual" strategies were tried: assessing signs/symptoms, giving medications, educating the patient and family, listening to patient and family talk out their concerns, and providing options for what could be done. Normally, these strategies worked to resolve the issue. However, when they did not work, the participant engaged in a more in-depth analysis of the situation.

This more in-depth analysis began with a participant's reconsideration of the patient's situation with respect to how the patient's QOL (i.e., symptoms, fears) was affected by the broader context of the patient's current surroundings. This included examining how the patient's circumstances (e.g., changes in clinical condition, functional ability, personal resources, coping ability), disease progression, expected survival horizon (i.e., days, weeks, months), patient-family dynamics (i.e., cohesiveness, enmeshment, disconnected, fighting), secrets (either acknowledged by patient or family member), and patient environment (e.g., personal residence, IPC, nursing home) might be affecting the patient and family members. A participant thought about the situation and tried to imagine what it would be like to be in the patient's situation, losing things that were important or not having control over what was once the taken-for-granted conditions of life (driving, being able to walk, feed one's self, work). This was the basis for many of the empathic verbal responses and creative options that the nurse suggested the patient/family try. Participant 18 reflected:

> You have to risk yourself too. You have to let them in for them to let you in. And you have to develop some kind of rapport, some kind of trust, a respect. And you have to be empathetic and to meet them where they are. And almost like you are transporting part of yourself into them to be able to understand them and understand where they are at. But then, you also have to be able to be detached to advise them, to recommend to them, and to help them through it. You become very involved with the family dynamics. But still retain that professional part to where you don't totally burn yourself out.

Participant 6 shared a patient care story concerning a woman with a non-healing wound, who was now becoming bed-bound and married to a man who had his own mental-health issues and did not fully grasp that his wife was dying:

> We observe this strange relationship between the patient and her husband…We recognize that the husband probably has some kind of personality issues that doesn't allow him to show affection…He can't do what we consider normal care things, you know, in terms of maybe getting her out of bed…or fixing dinner for her. She needs to have someone bring food to her. All these things and its not going on.…They've been married 30 years. They've learned to live with this relationship, whatever it is. But, it does impact her care. We feel for her, which kind of makes it hard to feel for him sometimes. But, we have to be able to step back and be able to look at this objectively and say, "What's in the best interest of the whole situation? Her, him, and even us?"

After considering the broader context of the patient's situation, the nurse then analyzed how the patient's past history and present situation could impact the patient's expected future. This was not done in isolation. While information and relevant points were initially talked about with the patient/family, the nurse also conferred with and brought in the other disciplines (e.g., social worker, chaplain, physician, bereavement counselor) to help gain insights, consider alternative perspectives, and develop strategies to ease distress related to the problem.

Equipped with the various insights, perspectives, and strategies, the nurse was now in a position to discuss goals with the patient and family. The purpose of these discussions was to come to some agreement over what was acceptable and achievable from the patient/family's perspective. As the nurse continued to consider what might happen in the patient's future during these discussions, the nurse continued to gently probe at issues that might eventually cause/heighten patient-family discord or prevent the patient from receiving adequate support (e.g., medications, emotional support, life closure activities) to see how strongly current beliefs were held to, what potential options might be, and where movement was likely to occur. Once agreement on the goal(s) were established, the nurse could work through developing an interventional strategy (e.g., medications, medical equipment, use of volunteers) to minimize the issue while shepherding the family's mental and emotional resources to cope with the current situation. Participant 21 remembered an eight-year-old hospice patient, the youngest of four children and only daughter whom the parents referred to as "Our Little Princess":

> Well, I came to know mom pretty well…I remember, I used to talk to mom and I used to tell her, "Mom, you know, the best thing you can do is show her right now, show her that you love her and be there for her. You know, express things to her that you've been holding back on." When she would push her other children away, I would talk to her about, you know, they are going to need some love and support because they've been the older brothers and they are going to want to

> share when the patient passes….It was a very sensitive time for the family, especially mom…I had to really stress that they needed to express their emotions. Just talking to them. Talking to them and finding the right time to bring that in…I just really had to make sure it was the right time, because mom was so sensitive to these topics.

When a nurse was fairly confident of the patient/family goal(s) and reasonable interventional strategies were apparent, then he or she conferred with the patient/family seeking endorsement of the plan. During these conversations, the nurse also considered the implications of the patient's survival horizon and how this would affect the urgency to intervene, timing of interventions, and evaluating the interventions' effectiveness. For example, Participant 20 described a plan she developed when working with the family of a 72 year-old gentleman diagnosed with end-stage chronic obstructive pulmonary disease who experienced frequent episodes of dyspnea. The patient's wife was very fearful that she would not be able to cope with any crisis situation and both daughters were nurses in a different state. Participant 20 shared:

> And I told each of them everything I was going to do and I even gave them my phone number and I explained we're going to make this work. We're going to keep him calm and everything's going to be comfortable. We're going to do everything we can to make it happen for him….[And time goes on] All along the way, the wife has been saying to me, "Okay, this is what you told me to do if he struggles, this is what I do, right?" Yep, yep, yep. It's posted on the side of the refrigerator. It's posted in the bedroom. Everything you're supposed to do if he has trouble breathing. Two days after his birthday, she calls me in the middle of the night. She says, "He's barely breathing." I said, "Is he barely breathing or is he struggling to breathe?" She said, "He's struggling." I said, "Okay do you want me to come?" And she says, "No, let me try those things you told me about and I will call you right back." About 15 minutes later she called me back and she said "He's breathing easier." ….They believed every word I that I said to them. They trusted everything I told them to do. Every time a problem came up, she [the wife said], "I got the list on the fridge, I'm going to try these things and if they don't work I will call you."

Once the plan was approved by the patient/family, it was the responsibility of the patient/family to implement the plan. The nurse's responsibility was to ensure that the patient/family had the resources (e.g., medications, medical equipment) to implement the plan.

Suffering

Participants identified their patient's suffering by trusting that the relationship with the patient (or family member) was sound enough that the affected individual would self-disclose what was occurring (e.g., pain, fear of impending death, relational discord, overwhelming sense of loss, inability to cope with a situation). The participant monitored and evaluated the relationship's strength by its degree of trust; specifically, the degree to which the patient and family "believed in" the nurse, confided what was happening within the patient/family context, and used the nurse as a resource that was listened to and suggested options acted upon. In this sense, trust meant that the patient/family had a reliance on the nurse as a person of integrity and a confident expectation that the nurse would act in the patient's best interests (i.e., the nurse meets the terms of the fiduciary relationship). As the participants observed and assessed the patient/family behavior, they made judgments regarding the relationship's strength and the degree of distress caused by the issue. After providing additional intervention options after a more in-depth assessment, which still did not resolve an issue, the nurses deemed the issue "suffering." Participant 3 shared about a 41 year-old gentleman with metastatic colon cancer:

> I could see the physical signs, but when I walk in I, I observe suffering with my eyes and with my heart. I can see the beautiful home, all these beautiful pictures…and I can see he wasn't sleeping so I talked with him a bit. He's worried. He's leaving a young family…. I sense it. You can hear it in the tone of their voice and you can see it…and they make little comments….I use the resources available and refer them to community resources, offer prayer if they need it, and just be there for them and walk with them.

In the course of the recurring, episodic nurse-patient interactions, certain situations also prompted participants to consider whether a patient might be suffering. These included the nurse:

- observing verbal and nonverbal clues suggesting a pain or symptom crisis not relieved by appropriate medications even at high doses,
- sensing a general unease when around the patient,
- hearing the patient express a lack of control over something that was important to him/her,
- observing a situation that suggested patient vulnerability,
- hearing the patient verbalize aloneness,
- observing the patient being isolated from others (e.g., patient bed in a different room that is shut off from family members),
- sensing a disconnect between the patient and family,
- observing a chaotic home environment (e.g., newly unkempt house, forgetting to pick up a child from school, tense body language between family members), and
- hearing families complaining about patient behaviors.

Reflecting on a patient that had a great deal of inner turmoil, Participant 22 recounted the conversation that finally enabled the patient to start moving past his suffering:

> This patient was a Vietnam War Veteran and he killed someone in Vietnam. But it's how he killed that always haunted him. So throughout his life he kind of pushed people away. And then it finally came out. He cut his [the enemy's] throat. And when you kill somebody that up and close and personal, it can really affect you….He talked to the chaplain about his regret… and then he was like "Thank you for being there." Sometimes it's the chaplain, sometimes it's the nurse, sometimes it's the CNA, or the volunteer [who helps the patient move].

Intervention

The participants intervened in their patients' suffering by alleviating physical distress and emotionally supporting the patient and family. Within the hospice setting, time is a valuable, precious commodity. The relational context of a hospice nurse's work, providing care to dying patients and their families, invited the participants to regard this time period as a difficult, frightening, and potentially meaningful period for the patient/family. The participants recognized that they were invited into their patients' lives because the patient was dying. This knowledge evoked a sense of feeling "honored" or "privileged" as they guided the patient and family to the patient's death. Participant 9 shared: "It's neat to be with them, to hear their stories…And so it's the story of their life, and at hospice, that's one of the values. You're put in a privileged position." Similarly, Participant 3 stated:

> I am grateful for the opportunities [of working with hospice patients]. I have the honor to go into this home and I am able to be of some support and continue to provide that support… Most of all, I just feel real honored to be able to bring them some comfort and reassurance.

Educating and emotionally supporting the patient and family were the cornerstone interventions for participants. Yet, as participants advocated for their patients, they also engaged in some unique interventional strategies: accepting, touching, sensing energy, and hoping.

Accepting.

One of the most fascinating strategies that the participants used was simply giving permission for people to feel the way they did and not need or want to change. Participant 6, reflecting on some of the difficulties patients and families have communicating with each other commented:

> [The dying] it's consuming their whole life….They get so wrapped up in that [their minds] that they can't open up and say "This is what I need." And your job becomes giving them permission…[helping them find options] giving them permission to say yes or no. It's okay. And we're going to support you in whatever those things you're telling us that you need.

This is congruent with the participants' attitudes toward accepting the patient and their family. Once again, this helped the participants to maintain the integrity of the trusting relationship with the patient and accompanying family members. For example, Participant 12 stated, "It's like wherever you are in life, its okay…. they don't know where they're supposed to be at. And it's like nobody does. It's like it's okay. Well just work through it together."

Responding to patient suffering is hard work requiring a great deal of emotional energy and mental alacrity on the participant's part. Through the use of their communication skills, the participants used the connections fostered by their ongoing relational investments to convey care to their patients. In a very deliberate way, the participants listened and validated the patient's experience focusing on accepting the patient. The participants' acceptance enabled the patient to explore difficult areas and accept one's self. While points of alignment with the patient were reinforced by agreeing with the patient's wish(es) for different circumstances, the participants maintained a present focus by giving permission to their patients to be where they were at or to make a different choice now if desired. These conversations further reinforced the connection between the participants and their patients creating safety for even more difficult conversations to occur later in the relationship.

Participant 20 shared this experience of caring for a 28 year-old gentleman dying from a pericardial mesothelioma. When this nurse first met the patient and his mother, the mother was very upset, had a cold demeanor and made frequent curt demands of the nurse. As the relationship progressed, the mother, while still angry with her son's impending death, became more available to supporting her son. Subsequently, the son started opening up about his needs. Participant 20 recounted a recent visit:

> He shared: "I've been doing a lot of thinking." And I asked him about what. And he said "I guess it would be about mortality. I said "Are you thinking about the end of your own life?" He said "No, I'm thinking about why I don't' want it to be the end of my own life … Are you guys going to help me sort this out?" And I said "Every bit that we can." And he said "Ok because I'm going to need to somebody to talk to." So he knows he's got some sorting to do. And he's willing to try…if you're going to face it, you got to have somebody that will hear you."

While nurse-patient conversations generally focus on the needs of the patient, the participants may have strategically self-disclosed relevant personal anecdotes to level the relationship. In a sense, this self-disclosure kept the relationship balanced. When a patient trusted a participant enough to confide difficult circumstances, the participant also demonstrated that the patient was trusted as well. For example, Participant 12 shared a story where she disclosed her son's death to the mother of a dying 31 year-old son:

> And the mom was just falling apart because her son. She kept coming to me and saying, "But my son was a good boy. He was good, and I don't understand why he's dying. He was good and he's suffering so much." He was. He had a lot of pain. And to watch him, that was really hard. And so the way I could bond with her—because she had such a hard time with her son because she would always say, "But you don't understand. That's my son and he's so young." And so I told her, "I can understand. I have a son that died too." And not many people will I tell that to. And every time I saw her after that, she would hug me. We bonded because she knew I did understand, we walked in the same shoes. You don't meet many moms that are fixing to lose their child in hospice. And I'm not talking about a baby, I'm talking a grown man in his thirties.

In summary, the interventional strategy of accepting relied on the participant emotionally supporting the patient/family by listening to them and sometimes sharing personal stories from their own lives. During these conversations, the participant was very mindful of the patient's/family's vulnerability seeking to protect their dignity and generally providing a sense of calm acceptance.

Touching.

As part of assessing and responding to patient suffering, the participants frequently described the importance of touching the patients, usually by holding their hand, touching their fore-arm, or hugging them. Initially, the touches were used to probe how accepting the patient was of the nurse and to gauge the patient's need for physical control of their body space. For instance, a stoic patient might allow the nurse to shake hands with him at the beginning and ending of an encounter but deflect all other attempts at touching. A patient in need of emotional support might allow a handshake at the beginning of the visit, hold the nurse's hand while engaging in a difficult conversation with the nurse, and initiate a hug at the end of the visit. For instance, Participant 8 shared:

> [Touch] it's very important. Until I find out that they don't like to be touched. (laughs) And there are those. But, I think it kind of closes a gap between the nurse and the patient. We're now one. You know? We're together. And if touch is soothing, then I keep doing it. And I kiss them good-bye too. And hug the families too. To me it's important. Now there are people that don't like to be touched and don't like to be hugged. And so I don't. But I'll at least shake hands. But, I think for the patient's sake, most of the time, it's appreciated.…[It's telling the patient] you're not a leper. I'm not afraid of you because you're a dying person.

An interesting point brought up by some of the participants was the recognition that the patient's social world was decreasing and with it, the ability to connect with other people. If the patient's physical experience included pain or other distressing symptoms (e.g., nausea/vomiting or dyspnea), family members would also decrease their time around the patient and almost become fearful of hugging or otherwise touching the patient. These participants recounted that often times, they would physically hug or otherwise touch the patient in order to give permission to the family that touching the patient was acceptable; dying was not a communicable disease.

Sensing energy.

An intriguing aspect of the participants' intervention strategies had to do with how they assessed the patient's/family's situation. During their assessments, many of the participants had a sense that they felt an energy in the room, surrounding the patient. Various participants interpreted the energy differently. Some referred to it as a tension, an "unease," or a person's spirit. For example, Participant 18 stated:

> You have to be discerning, able to look people in the eye. And you can tell if their spirit is open to you or not….You pick up on that. And you can pick up on "They don't want me at the house." or "Yes, they're so inviting to me." …This is not something I normally see shared among the nurses unless the nurse is your best friend. Okay? Or it's a bad vibe, they'll tell you about that.

Relatedly, Participant 22 shared:

> The best way I can explain it [the energy] is when you look and sense something. It's kind of like sensing danger. The only difference is how it feels, like a tension. Like most people have walked into a room and something's going on there. You feel it. It's a feel. And it's the spirit.…Sometimes from the patient, sometimes from the family… and I can't always put my finger on it, but there's something going on and I have to relieve it….And when it relaxes, they all look comfortable.

Participant 12 recounted a disconcerting experience:

> This particular one, it was so strong. The patient was pretty much unresponsive. And you would walk in there and she'd like growl…so, I would go in there with the other nurse [to reposition the patient]. And I just kept hearing it and I thought it was spooky. And so when we walked out of there, she [the other nurse] goes "Ooh! Did you feel that?" And I go "Yeah." She goes, "It sounded like she [the patient] growled." I go "Yep. Exactly. I keep hearing her growl." And its like I don't understand all of that, what's actually going on. But I know something wasn't good going on in there.

Each of the participants who discussed sensing energy from the patient indicated that interpreting this energy was part of their assessment and the interpretation provided direction for the next step in the patient's care. When the energy was interpreted as peaceful or calm, the participants used this as an indicator that the patient was at ease and the death would be peaceful. Participant 12 stated:

> You go in, and like you can feel this patient's fixing to die but you still have a peaceful feeling around them, when you go into there. And so when you do that, it's okay. You know it's going to be a good death. And ultimately that's what you want, a good death.

Conversely, the nurses also sensed energy that indicated the patient's death would be difficult. Participant 9 shared:

> You're always assessing what's working and what's not working. The physical and the psychosocial phenomena around the patient…There are phenomena that no one else can witness…I've observed and most nurses I've talked with think or observe that most people make it to heaven, meaning there was calm, a sense of peace in the room. They looked relaxed. And we have had a couple others who were extraordinarily afraid, looking at the floor, watching the floor as though someone or something was coming through it. We had this one young man in his 20s…he was scared. In fact he was screaming. He was definitely—he was moving backwards in the bed. He was moving against the bed, away from whatever was coming toward him.…There was so much negative energy that they [the nurses assigned to him that day] couldn't enter the room.…The nurses felt stopped at the doorway and after he died and went into the room, could feel the sadness. They felt so sad inside that room, like the negative energy had taken…surmised that he did not go to heaven.

These difficult deaths were hard on the participants particularly when they interpreted this as failing their patients.

Hoping.

As an interventional strategy, hoping enabled the participants to maintain a personal sense of optimism that they were able to share with the family. This optimism focused on being present-centered, focused on maintaining or improving QOL today even though the patient was declining. By being able to maintain a time orientation focused on an expanded present, the nurse and the patient/family were able to continue to express hope for the "now" and realize these hopes in the immediate future, which could be a source of comfort. The participants listened to their patients and family members share current concerns and their dreams and fears they had of the future. Participant 3 reflected:

> The last thing you lose is hope. I accept them (the patient and family)… It's about them. We come into support; we're not taking over. And that right there gives them power. They're still in control…that's where the hope is and their will, because they have the control….As I say, you can be very direct with a gentle attitude. Pick your words carefully, they (the patient) will guide you.

Participant 9, contrasted hopes she heard shared by families of her pediatric hospice patients and her adult hospice patients:

> Parents are hoping they're [the child] going to get healed. Something's going to happen. And all of a sudden, it becomes "Okay, I don't want him uncomfortable, just be comfortable." And then a hope of "I don't want them to be scared of what's going on." And then, I hope I can make them happy to the end." Its like stages of coming down to realizing that, okay, it's the end. They know it. The end is here….Adults, they hope they're going to get better, or it's the faith itself. "It's God's will. I'm going to pray. I'm going to get better." And they lose that God's will part…and they get angry, hurting. I tell them, "You're faithful, God's will is going to happen whatever's going to happen. If you don't get better, it's not because you weren't good enough to get better. It's because it's God's will."

In summary, the participants actively engaged with their patients and their families to identify and respond to their patients' suffering. They used a four-phase process that included observation, issue assessment, suffering, and intervention to resolve suffering in their patients. As part of their interventions, the participants engaged in the unique strategies of accepting, touching, sensing energy, and hoping.

HOSPICE NURSES' COPING STRATEGIES

This section addresses the third study aim, which is describing the personal coping strategies that hospice nurses use when working with patients they perceive as suffering. Interestingly, many of the study participants had a difficult time discussing how they personally felt while working with suffering individuals. Their patient encounters seemed so other-focused that they could not or did not recognize their own responses during the interaction. However, the participants acknowledged feeling emotionally and mentally drained after interactions with their hospice patients/families. Generally, they would try to give themselves a few minutes in their cars to recenter themselves before proceeding to their next patient's residence. For the IPC participants, they tried to take a few minutes in a quiet place such as the clean utility room where they could be alone while recentering themselves before going into the next patient's room. For example. Participant 11, a field nurse, shared:

> And sometimes you go out [of the house] and take a deep sigh….I have in my trunk a cushy teddy bear. And when I'm so frustrated or I'm so sad, I go out and hug it before I go to the next patient. I go out and I've got some tapes, some CDs that I listen to that put things back in perspective. They're musical and it helps me realize where the control is…and it helps me unwind.

The researcher's invitation to discuss their personal reactions to working with patient/family suffering was often initially met with a silence. At first, the participants struggled stating they did not understand or were dismissive of these questions stating it was just part of their job, dealing with hospice patients in crisis. After acknowledging these points, some offered that by the end of the day, they were too tired to do anything at home. For example, Participant 12 shared:

> I have a hard time sleeping at night, I just carry it. Its very hard, I can tell you….For me, I'm going to sit on my deck and not think about anything. And then I'm going to watch TV…. just to get my mind off of—because it's just to heavy to carry with you all the time.

Some participants shared their perceptions of attributes that enabled them to continue to work in hospice nursing. Interestingly, these attributes revolved around the nurse's acceptance of death, people, and desire to connect to others. Particular attributes that the participants identified were:

- recognizing that people die,

- accepting that their patients would die,
- acknowledging that they would become emotionally close to some of their patients,
- realizing the death of a patient could affect the nurse,
- accepting their patients for who they were,
- accepting themselves, and
- being able to empathize or accurately imagine and feel what another person was going through.

Participant 9 stated, "It [Hospice nursing] validates everything you believe and it challenges you…Again to do hospice, you've got to have your own values about death and dying intact because you're really going to live them." Or as Participant 6 shared:

> The people who do best in hospice have a certain philosophical position that allows them to deal with the fact they're going to lose their patients…we know where this is going to end. And you have to be able to deal with that. And if you can't, you shouldn't be in hospice because its too hard. Too hard on your patients, too hard on you. Because you're not going to be able to deal with it.

Rewards

These participants found certain aspects of working with hospice patients rewarding. First, there was a sense of being honored or privileged to be the one individual in the patient's/family's life that could make the patient's life better. During these times, the participants spoke of how grateful they were for the opportunity to work with the patient/family, confidence in their skill-set, and of how victorious they felt when there was issue resolution. Another important reward for these participants was the sense of sharing a strong personal connection with the patient/family. This personal connection energized the participant and often provided enough motivation to overcome any negative experiences the participant was going through with that patient. Participant 3 offered:

> I don't know how to explain this, but sometimes the patient will do something and its like my heart opens up. Its like a feeling of warmth or something and "You're in there!" Yeah, like its some little quark, it's different and I don't always get it but its something to do with me emotionally and my brain—I had one patient, he was a real bear. I couldn't find anything good about him. Anyways. I was pushing a drug in his central line. While I was pushing this drug, he touched my cheek and I thought he was going to hit me, okay? But no, all he did was touch my cheek and looked at me. And I thought "Wow." There's tears in my eyes 'cause he's a bear. He was not a nice patient. But from then on, we got along. I can't explain. God was there. That gives me faith it will happen again.

Costs

Even though the participants initially had difficulty identifying personal responses they had to working with their suffering patients/families, some eventually opened up regarding how emotionally draining the job could be. Within the context of stressors about their jobs, they discussed needing time to process through some of their emotional reactions to what they witnessed.

Within the context of needing time, the participants related feelings of sadness, anger, helplessness, and frustration after patient encounters. Sometimes these feelings would become more pervasive, crowding into other patient encounters or being recognized as interfering with the participant's personal life. There were even times these feelings become more global and the participants shared that there was just a sense of mourning about them or that they were "broken" by the job. During these times, they related they could not hold it together anymore, needing time to cry, and were emotionally shut down unable and unwilling to emotionally engage with their patients or families. Participant 8 shared:

> Periodically during the year each year, it'll come to my mind when I meet a new patient and I really like them that they're not going to be there in a year. So I'm not getting close to these people. You're going to be dead in a year. I'm not going to talk to you. But I get to, I always get close to them and I don't feel like their experience is going to be as good as it can be unless I am that personal with them and their family. And these times during the year, I just cry. I'll just cry for the situation I'm in. And you know, I hate to see another person die. And, oh, I loved Mr. So-and-So, you know? I drag around for a few days. And then, I guess, my spiritual life will get me back into, in touch with "You're doing something important and I'm going to give you extra strength to do it. So just keep doing it." I guess to be good at this, you need to get their trust, and sometimes that does involve giving your heart to them, giving of yourself to them….people that can't block that pain and hurt until later (after the visit) or they're crying all the time. They can't do it. They can't continue to do this and not get overwhelmingly depressed.

Coping Strategies

Interestingly, the most common answer participants gave to questions related to their own self-care was "nothing." Even though they endorsed the idea that self-care was important, they often had difficulty identifying any actions they took to care for themselves. While they initially focused only on physical activities, common ideas regarding their mental, emotional, and spiritual lives became apparent. For instance, participants related the importance of knowing themselves, being comfortable with who they are, being emotionally mature because they would frequently be confronted by death and other people's poor reactions, and being comfortable with their spiritual beliefs, especially as it related to the afterlife (if any). Within these spheres, they discussed stresses related to patient/family situations that caused some people to say hurtful things to the nurse. While it was unfair and sometimes emotionally wounding, these attacks were not considered personal. For instance, Participant 7 stated:

> They may be hiding their feelings, but they're angry because of the situation that they're in. And sometimes they tend to lash out at you. You know? But, we can't take it to heart. It's just because of the situation that they're in. And we have to be understanding…I may need to walk out of the room. Get myself together. Ask the

> Lord to give me strength and not allow me to hurt someone else because I am hurting at the time…. You have to have a lot of [emotional] strength. But you have to have a lot of faith too.

A frequently shared coping strategy was the participant talking with a spouse, coworker, or friend to work through the weight of heavy emotions and difficult patient encounters. Many times they did this to let someone else know what they were going through and so they might gain ideas about how to handle a situation. In addition to sharing how these challenging interactions currently affected them, they also needed reminders that the situation was temporary. Participant 19 reflected:

> We're all human. Sometimes it still hurts. And that's why I feel like talking it over with my colleagues, we're able to air it out. We're able to exchange ideas. They're very supportive….We're all here for the same purpose. And I think most everybody—When I've talked to them, our priority is the patient, and we have the common goal of giving the best quality of life to our patients. And all of us have a difficult family right now. And, they come and go….And we need to remember that.

As previously stated, the participants frequently related that difficult patient encounters left them feeling sad, drained, or frustrated. In the course of the day when these feelings became overwhelming, they shared that they often would take a few minutes to cry privately or recenter themselves before proceeding to the next patient visit or returning home to their own families. Sometimes though, a few minutes alone were not enough. They returned home and were not able to emotionally reconnect with their families. Instead, they would isolate themselves by watching a mindless television show or separating themselves from others so that they would not feel obligated to talk to anyone.

Boundaries.

Many of the nurses discussed the importance of boundaries in maintaining a professional relationship that was still intensely personal. The nurses discussed how boundaries facilitated their ability to turn off their phones and to "not be on" as a nurse when they were in their personal space. Participant 13 shared:

> I think we can be highly involved and still have a healthy boundary. Mostly, they are looking for you to care about them, to convey sincere and genuine concern. And they want informed guidance. And you can do that without making decisions for them….I do set boundaries now that I didn't when I was younger. You know? I can, in a nice way tell them, "This is where you can be a little familiar and try to reach me, but this is where the line is drawn. If you really need to reach me after 5:00, you need to know that I step away from the phone to take care of me." I think that helps right off the bat so they will respect you and your time.

The participants identified another important aspect of boundaries: that of not bringing their own issues into the nurse-patient interactions. They had to be able to separate what was going on in their own lives and the lives of other patients from the current patient's situation. Participant 18 reflected:

> I see a lot of nurses not taking care of themselves physically. I didn't take care of myself physically either, okay? Usually the age of the nurses that we have right now, they're sandwiched between grandkids or kids and parents that are elderly too. And so they're going in three directions at once and then trying to see they're patients and be on-call. Maybe for the time, they're not making it a priority. But physically, they have to take care of themselves to do this job. And then spiritually, you've got to take time for that also. Meditation, yoga, church, whatever you do to tap into your well. And usually, the nurses cannot handle it if its crazy on both fronts. If its crazy at work and at home, the nurse usually bites the dust because they can't be there for their patients. They can't handle that…They have to have someone in their life that they can share with, that's empathetic to them….When they don't have it, its awful. Actually awful. They leave hospice nursing. They can't carry it. Even good nurses. They could not do it if the well was dry.

In summary, this section described the participants' difficulty identifying their personal responses and coping strategies. They disclosed that by the end of their workday, they were often emotionally drained and sometimes not able to fully participate in their own lives. While they endorsed the idea of self-care as important, they often had difficulty identifying ways they personally took care of themselves. Once they were able to broaden the idea of self-care beyond physical activities, they did highlight various activities and ways they cared for themselves—talking to someone who was empathetic to them, engaging in their spiritual practices, and setting boundaries.

This chapter presented what hospice nurses identified as suffering in their patients and the process they used to resolve the suffering. Participants identified and responded to their patients suffering within the context of the hospice nurse-patient relationship. The participants invested time and energy to sustain these relationships. Phases of the relationship included: preparation, establishment, cultivation, maintenance, and letting go. In addition to pain and other signs of physical suffering, the participants identified other aspects of suffering: role losses, the patient's fear of the impending death, patient aloneness, and the patient's feelings of guilt or regret. Interestingly, suffering was also considered a family affair and could involve the loss of self-identity. The participants gained insight into the psychosocial and existential aspects of the patient's psyches by cultivating the nurse-patient relationship. Within this relational context, the participants used a four-phase process: observation, issue assessment, suffering, and intervention to respond to their patient's suffering. While the participants recognized the importance of self-care, they often had difficulty naming strategies they used to respond and cope with their patients' suffering.

Chapter 5: Summary, Conclusions, and Recommendations

The purpose of this study was to develop an inductive theory describing the process that U.S. hospice nurses use to identify and respond to their patients' suffering. Additionally, the study sought to describe the coping strategies hospice nurses used when they worked with patients they characterized as suffering. This study was significant because the evidence base for effectively identifying and intervening in patient suffering at EOL is sparse and by purposefully addressing patient suffering, it is conceivable that a patient's QOL could be improved. Additionally, gaining insights into nurses' coping strategies may provide a foundation to develop interventions that hospice nurses could use to care for themselves while working in a hospice setting.

Grounded theory methodology, as described by Charmaz (2006), was used to guide the design and data analysis. A purposive sample of 22 hospice nurses from the San Antonio, TX area was recruited to participate in one-to-one interviews. Constant comparative analysis was used to analyze transcripts, field notes, and memos. Based on the emergent analysis, axial and theoretical coding were used to pull the data together forming it into a cohesive whole.

Participants identified and responded to their patients' suffering within the context of the nurse-patient relationship. They viewed themselves as advisors investing time and energy into building and sustaining trusting relationships with their patients. Phases of the relationship included preparation, establishment, cultivation, maintenance, and letting go. Through the lens of relationship, the participants identified and empathized with multiple aspects of suffering: unpleasant symptom experiences (e.g., pain, dyspnea, nausea/vomiting), role losses, fears related to impending death, aloneness, and feelings of guilt or regret. The participants also recognized that suffering could cause a loss of self-identity and could be a family affair. In order to respond to their patients' suffering, the participants used a four-phase process: observation, issue assessment, suffering, and intervention. Even though the participants endorsed the idea that self-care was important, many had difficulty naming personal-care strategies they used while responding and coping with their patients' suffering.

This chapter will present a discussion of the study's findings with implications for clinical practice and recommendations for future research. A summary of the evaluative criteria (credibility, originality, resonance, and usefulness) will also be presented.

DISCUSSION OF FINDINGS

Participants in this study identified categories related to their patient suffering providing support that some U.S. hospice nurses do identify suffering within their patient populations. An unique facet of this suffering was the participants' identification of a familial suffering. There are areas of consistencies and inconsistencies between this study and prior studies regarding when and how hospice nurses select intervention strategies. Also, these participants suggest that the hospice work environment may mitigate (or exacerbate) their ability to cope with their patients' suffering. The following is a discussion of this study's findings.

Nurses Identifying Patient Suffering

Overall, scant attention has been paid to how nurses identify and respond to their patients' suffering at EOL. Prior studies have shown that nurses do identify patient suffering but often do not know what to do in response to the suffering (Breaden et al., 2012; Martins & Basto, 2011; Rydahl-Hansen & Eriksen, 2009; Thorup et al., 2012; White et al., 2004). Currently, there is no clear evidence base to guide practice focused on the identification and alleviation of patient suffering at EOL. Previous studies indicate that even without a clear evidence base, nurses have developed anecdotal strategies to work with patients they regard as suffering (Breaden et al., 2012; Martins & Basto, 2011; Mok et al., 2010; Rydahl-Hansen & Eriksen, 2009; White et al., 2004). These strategies include attending to pain/symptom management, altering the environment to accommodate the patients' particular needs, sharing a sense of hopefulness for the patient, and learning to "be with" the patient instead of trying to "fix" the patient.

In this study, the participants used a multiphasic process that required ongoing attention in order to build and maintain trust that allowed them to address their patients' suffering. Repeatedly, participants identified their main goals as optimizing their patients' QOL and orchestrating a peaceful death for the patient. Bounded by the context of the nurse-patient relationship, the participants observed, assessed issues, identified suffering, and intervened to relieve their patients' suffering. The nurses monitored these relationships gauging patient trust by the patient's degree of self-disclosure and how consistently the individual tried interventions suggested by the nurse. For these participants, fidelity to their patients included relationally caring and educating family members in an effort to bring comfort and calmness to difficult situations.

One of the differences between this study and prior studies is the nurse's starting place for identifying and responding to suffering. Prior studies often begin with an acknowledgement that the patient is suffering and the nurse actively seeks out the signs of this suffering. For instance, the Rydahl-Hansen and Eriksen (2009) study set in a Danish palliative unit found that nurses first attempted to explain and mitigate physical signs/symptoms, but only sought out indicators of "suffering" after the physical signs did not resolve and it was late in the shift. Even though the current study specifically examined "identifying and responding" to suffering, the participants began with a focus on QOL. In essence, the nurse might not identify suffering if it did not interfere with what the nurse understood as QOL for the particular patient. As the current study progressed, it became clear that the nurses "identifying and responding" to suffering was a subprocess of their building and maintaining trusting nurse-patient relationships.

Martins and Basto (2011) sought to understand the intervention process nurses in a Portuguese oncology-palliative unit used to relieve suffering in their EOL patients. They identified patient accompaniment as the basic process, which begins with the nurse's perception of a patient suffering and then the nurse actively seeking to alleviate that suffering. Within Martins and Basto study, in-between the nurse identifying a patient's suffering and the nurse actively seeking to alleviate the suffering was the nurse's own recognition of self-suffering. This self-suffering could effect the care the nurses provided to the patient.

Nurses Responding to Patient Suffering

Regarding how and when nurses choose to respond to their patient suffering, prior studies included various strategies that hospice nurses use when working with suffering patients (Boston & Mount, 2006; Breaden et al., 2012; Martins & Basto, 2011; Mok et al., 2010; Rydahl-Hansen & Eriksen, 2009; Thorup et al., 2012; White et al., 2004). Due to the scarcity of research in this area, previous research findings sometimes leave the reader with the impression that the strategies used to work with suffering patients are unconnected to the current patient situation; the strategy may be selected based on a previous experience with a different patient instead of individualized to the current patient situation. Findings from this study suggest that the participants' strategies are deliberately chosen and thoughtfully used. Sound symptom management coupled with strong interpersonal skills became the gateway nurses used to establish rapport and quickly build trusting relationships. The unifying characteristic in selecting a particular intervention strategy was the nurse’s understanding of how the strategy’s use, misuse, or nonuse would affect the patient’s current QOL and the on-going, nurse-patient relationship, which might prevent the nurse’s ability to orchestrate a peaceful death.

Findings from this study suggest that some U.S. hospice nurses develop awareness, identify suffering, and respond to alleviate suffering within their patients through the context of cultivating trusting nurse-patient relationships. This is the first study specifically examining this issue in U.S. hospice nurses. In a recent integrative review, Zolnierek (2014) found a nurse’s knowing the patient was a very personal process that included the nurse’s awareness, cognitions, perceptions, experiences, and reflections as the basis for determining how the nurse responds to a patient. Over time, these acts of engagements form a specific nurse-patient relationship that is meaningful to both nurse and patient. In Zolnierek’s view, a nurse’s skill in knowing the patient affects the nurse’s ability to provide safe care, develop positive relationships, and engage in expert practice.

Prior research concerning patient suffering at EOL consistently identifies the following themes: physical symptom experience, psychological distress, emotional isolation, and identity changes (Abraham et al., 2006; Bruce et al., 2011; Chio et al., 2007; Rydahl-Hansen & Eriksen, 2009; Sacks & Nelson, 2007; Sand & Strang, 2006; Williams, 2004). The physical symptom experience concerns how the suffering individual’s symptom (e.g., pain, dyspnea) dominates the life experience as the individual tries to make sense of what the symptom means in terms of disease process, treatment, and/or nearness of impending death. The psychological distress is related to the suffering individual’s ruminations about the meaning(s) of the symptom experience and accompanying life circumstances. This concern may expand to consume all emotional energy; thereby, overwhelming the individual’s coping abilities while increasing the uncertainty and vulnerability associated with unfolding circumstances. The symptom experience and the psychological distress can "feed" into each other, exacerbating both. Emotional isolation has to do with the suffering individual's sense of isolation (even in the presence of other people) that prevents the sufferer from making one's needs known. This sense of isolation often leaves the sufferer with feelings of worthlessness. Identity changes concern the suffering individual's sense of a changed inner reality. Through the lens of "being a burden," the sufferers describe changes in roles and relationships.

Recalling Kahn and Steeve's (1986) definition of suffering as an individual's experience of threat to self coupled with the meaning(s) attached to an event or loss, a suffering individual may no longer have confidence in knowing one's self or that one's perceptions of realities are "correct" (Sacks & Nelson, 20007). This can create a sense of uncertainty and vulnerability for the sufferer. As the suffering individual enters into conversations, the sufferer seeks feedback as he/she "tries out" different versions of one's story to see which story (explanation) others accept from the sufferer. The sufferer then examines whether this accepted version is actually true to the sufferer and if so, how to begin accepting it as part of one's self (Sacks & Nelson, 2007). Nurses (and others) entering into conversations with suffering individuals may not realize the impact their reactions may have on the sufferer as the sufferer is literally in the process of creating or affirming his/her identity.

Participants (nurses) in this study emphasized the importance of the nurse-patient relationship as a pre-requisite and co-requisite for identifying patient suffering. It is through this relational context that "suffering" became evident. And its manifestation prevented the nurses' from achieving their immediate goal of patient comfort. While pain was often the first identified characteristic of suffering, any physical symptom not relieved by the "usual" doses of medication was further investigated. Other aspects of patient suffering included role losses, considerations of the patient's impending death, patient aloneness, and feelings of guilt or regret as different aspects of suffering. Additional aspects of suffering included viewing suffering as a family affair and recognizing the loss of self-identity.

This study's participants' experiences were consistent with each of the major themes from the aforementioned studies related to patient suffering at EOL. The current study's findings provide additional evidence that hospice nurses do have an awareness of what constitutes suffering within their patient population. In general, this is reassuring. However, it remains unclear to what degree the nurses appreciated how overwhelming the ongoing experience of suffering could be. Differing perspectives held by the nurse and the patient may contribute to this potential disconnect resulting in nonresolved suffering. From the patient viewpoint, a certain level of trust is needed in order to initiate disclosure of an experience as "suffering" (Boston & Mount, 2006; Sacks & Nelson, 2007). The patient may try to minimize the situation by putting a positive slant on what is occurring either from a desire to please (i.e., be a "good patient"), or from a belief that nothing could/should be done to mitigate the situation (Chio et al., 2007; Nilmanat et al., 2010; Rydahl-Hansen, 2005). Additionally, various expectations—stated and unstated, personal and familial—might influence disclosure.

From the nurse's viewpoint, the nurse may actually appreciate how overwhelming the situation is, but not have any personal strategies to deal with the emotional or existential demands of the suffering, and consequently not address it (Martins & Basto, 2011; White et al., 2004). The nurse may hold the belief that responding to suffering is the purview of other team members, so the nurse only addresses the physical aspects of suffering in order to minimize symptoms while a different team member (e.g., counselor, chaplain) addresses the other aspects of suffering (Breaden et al., 2012; Mok et al., 2010).

Alternatively, the nurse may simply not be in a position to address suffering on a given day due to high workloads or personal agendas focused on technical task completion. Another consideration is that not addressing the suffering is self-protective for the nurse, particularly if the nurse is already emotionally spent from dealing with the cumulative loss, grief, and suffering of other patients (Thorup et al., 2012). Regardless, any of these factors or other unnamed ones could be contributing to this potential or actual disconnect between the patient and nurse. And this disconnect prevents the nurse from grasping the significance of the patient's suffering.

The study participants navigated between many categories of people (e.g. patients, family members, hospice nurses, physicians, ancillary services) with different expectations, needs, and language use. As part of their role, the nurses adapted their persona based on whom they interacted with. So, when the nurses talked with a patient or family member, they used "lay" terms; when talking with physicians, they used technical terms. This contributed to the participants easily identifying many different aspects of suffering, but obscured their synthesizing these disparate aspects into a single phenomenon of suffering.

For the participants, each aspect of suffering existed as a separate issue that had no relation to other issues until they engaged in a more in-depth assessment of the issue. At that point, they could label the issue as "suffering." For instance, the participants readily identified physical pain as a potential aspect of suffering. Initially, pain would only be considered a symptom issue that needed to be addressed by finding the appropriate analgesic regimen. However, if the pain was accompanied by declining functional status and resulting role changes, then the symptom constellation constituted suffering. Interestingly, the participants never spoke about what the pain actually meant to a patient. When questioned about this, the participants reported that no IDT member had ever asked them the pain's meaning for the patient or suggested that they ask. Similarly, no physician wanted to know what the pain meant; the physicians only wanted to know what type of pain it was, severity of pain, and previous pain medication regimens. In this way, the nurse met all role expectations, but did not have an understanding of what the symptom experience meant to the patient. An understanding of what the symptom experience means to the patient could provide direction to what the patient expects in regards to its management.

Participants in this study actively sought to comfort their patients as a way of alleviating the immediacy of suffering. Prior research (Benzein & Saveman, 2008; Berg & Danielson, 2007; Evans & Hallett, 2007) suggests comfort is highly valued by patients with touching and conversation as the primary interventions nurses use to provide comfort. As Green (2013) points out, nursing is one of the few places in contemporary society where physical touch is accepted and even expected at times. Touch is important in its meaning and its ability to comfort and soothe; which supports other care activities.

Inherent in comfort care is a practice wisdom, which is a synthesis of knowledge, experience, intuition, and an understanding of how to enter the other's world in order to be with that person (Evans & Hallett, 2007). As a comfort intervention, conversation with a patient (or family member) affirms the individual's dignity and worth (Benzein & Saveman, 2008; Berg & Danielson, 2007; Evans & Hallett, 2007). When communication is characterized by nonjudgmental acceptance where the individual is encouraged to express feelings, worries, and concerns, there is a possibility of creating alternative ways of thinking and subsequently choosing different options, which may potentially induce hope in the patient.

Tapp (2001) advises that all nurses need the interpersonal skills to be able to engage and facilitate conversations with patients and family members regarding the effects of the patient's illness on all family members. Many of the participants discussed their participation in multiple conversations they initiated to open communication between the patient and family members. This seemed to occur more often when the nurse encountered a sense of isolation between the patient and a family member or when there was a sense of "unfinished business" regarding an issue or relationship (e.g., patient wanted to reconcile with a family member, patient wanted to discuss one's dying openly). This study provides some evidence that hospice nurses either come to the hospice setting with an interpersonal communication skillset that facilitates these conversations or they develop this skillset through their work interactions.

Intriguingly, the participants also viewed their patients' suffering as a suffering that could extend to encompass the family, with each family member isolated by their own personal suffering and also connected by a joint suffering. This is a novel finding. While this may be a by-product of the nurses being enculturated into hospice with its focus on family as the unit of care, it is conceivable that hospice nurses are more attuned to this aspect of suffering than nurses in other settings. In a sense, this aspect highlights the sufferer's tension between feeling of isolation and longing for connection. Considering suffering as a solely private experience may underestimate the connection the sufferer has with others, especially from the sufferer's viewpoint. An additional consideration is that private suffering may also be self-protective in the sense that isolation may protect the sufferer from others' potentially poor reactions.

Nurse Coping

Regarding how nurses personally cope when they work with suffering patients, this study and other studies indicate that nurses do need various coping strategies in order to continue working with hospice patients over long periods of time. Prior studies indicate that working with suffering patients negatively impacts the nurse (Boston & Mount, 2006; Breaden et al., 2012; Martins & Basto, 2011; Mok et al., 2010; Rydahl-Hansen & Eriksen, 2009; Thorup et al., 2012; White et al., 2004). Feelings of distress, sadness, failure, and "being overwhelmed" are common experiences. As a whole, these studies indicate that nurses need emotionally supportive environments conducive to sharing what is happening to them and allowing them to work through the continual experience of cumulative grief. Researchers frequently reported that nurses had difficulty maintaining boundaries between caring for their suffering patients and their personal lives (Boston & Mount, 2006; Breaden et al., 2012; Thorup et al., 2012; White et al., 2004). Various coping strategies used by the nurses in prior studies include taking time off of work, exercise, hobbies, participation in religious activities, talking with other people, and some had left working in EOL care settings. These aforementioned studies also offered the important insight that being able to successfully deal with their patients' suffering was a motivator for the nurses to continue to work in EOL settings.

In this study, participants struggled when discussing their own responses related to their patient suffering. Two themes characterized this difficulty. First, their patient encounters are so other-focused, that they either did not recognize responses geared towards themselves (e.g., fear, sadness, fatigue) or they could not recall these aspects of their patient encounters. Secondly, while they could identify after-effects of these patient interactions such as emotional fatigue, there seemed to be a resignation that it was "just part of the job" and therefore, nothing could be done about it. Interestingly, even though they were hesitant to name self-responses, many participants later verbalized a desire for a time and place where they could work through the emotional weight they felt. The participants were able to share attributes they considered important in being able to continually work within a hospice setting. These attributes revolved around the nurse's acceptance of death, people, and a desire to connect with others. They also identified intangible rewards that motivated them to remain working in hospice settings. Among these were feelings of being privileged to work with these patients, confidence in their skill-set, and how victorious it felt to facilitate an issue resolution. Initially, the idea of self-care seemed to only incorporate physical activities. These participants experienced difficulty identifying coping strategies in relation to working with suffering patients. However, coping strategies related to work-life rhythms, emotional maturity, and comfort with their spiritual beliefs (especially relative to existential issues) became much easier for the participants to identify and explain when these were discussed in relationship to their hospice work.

Unlike the aforementioned studies that indicated working with suffering patients negatively impacts the nurse, findings from this study suggest that while the nature of the hospice work environment partially contributes to the negative impact, the environment may also mitigate this impact by providing constructive avenues to dissipate this stress. While individual encounters with suffering patients do impact the nurses positively and negatively, the ongoing nature of repeated encounters with multiple patients experiencing their own unique suffering across time also contributes its own impact. This seems analogous to an individual with heart failure. Heart failure is a chronic condition that the individual learns to manage over time. Given enough stressors, the individual will experience an exacerbation that must be dealt with in an urgent manner. The exacerbation overwhelms the usual management strategies and necessitates special, "acute" measures for relief. Noticing and responding to suffering is just one thing among many that the hospice nurse does in the course of the work day and over the course of nurse-patient relationships. It may be that the nurse's perception of "normal" eustress versus distress is the indicator for when, how, and to what extent "acute" measures need to be taken. If this is the case, then facilitating work environments that could promote nurses' self-care and having resources available for the "acute" times that provide the nurse with emotional support (e.g., someone to listen while the nurse vents feelings) and practical aids (e.g., colleague to problem solve with or clinical supervisor to adjust nurse's schedule that day) may be a potential solution.

This study did have points of congruence with other studies regarding nurses' coping strategies (Boston & Mount, 2006; Breaden et al., 2012; Martins & Basto, 2011; Mok et al., 2010; Rydahl-Hansen & Eriksen, 2009; Thorup et al., 2012; White et al., 2004) in the sense that there is the same sense of being overwhelmed at times and the same coping strategies were repeatedly identified. Coincidently, nurses in this study seemed to have the most difficulty with boundary work and consistently engaging in coping strategies when they were novice hospice nurses. While not the focus of this paper, participants frequently commented how hard the first one to two years were as they negotiated their new roles and learned when, where, and how to place appropriate boundaries. Also, during this time, there seems to be a certain introspection as they matured into the role and became more comfortable with the spiritual and existential aspects of hospice nursing. As nurses, they live in a world of varying survival horizons. Their patient's horizon is near while the nurse's and the family's are more distant. This provided a dual perspective of time as short for the patient and long for the nurse and family member. From this perspective, the participants often identified areas of "unfinished business" for patients and family members that they would encourage open communication about. For the nurses, noticing these areas brought a sense of perspective to their own lives and influenced their personal relationships.

In summary, there are some consistencies and inconsistencies between this study and previous studies. In agreement with other studies, hospice nurses do identify when their patients are suffering. While other studies begin from “The patient is suffering.” viewpoint, participants in this study were very clear that they began from “What is my patient’s QOL?” viewpoint. Consistent with other studies, the participants did not have a defined knowledge base or prescriptive framework guiding their responses. However, they consistently used a very pragmatic process when working with patients they considered suffering. While previous studies identified strategies that nurses use to mitigate a patient’s suffering, this study identified the unifying characteristic in selecting a particular strategy was the nurse’s understanding of how the strategy use, misuse, or nonuse would affect the patient’s QOL and the on-going, nurse-patient relationship.

Additionally, this study offers a different aspect of how working with suffering patients’ personally affects the nurses. Previous studies seem to attribute the majority of the negative impact on nurses when working with suffering patients to the notion that this impact is derived from the interaction with the suffering. Findings from this study suggest, that the nature of working in a hospice setting may contribute to and mitigate any negative impact on the nurse. Important to the nurses was having someone to provide emotional support and practical aid when their personal coping became overwhelmed. Findings from this study also suggest that nurses experience some sort of personal growth process that is meaningful to them as they mature in their hospice-nursing role.

CLINICAL IMPLICATIONS AND RECOMMENDATIONS FOR PROFESSIONAL DEVELOPMENT AND RESEARCH

Minimal prior research addresses how nurses identify and respond to patient suffering. None of the prior studies, reviewed in this dissertation, focused on nurses practicing in the U.S. Previous studies found that suffering is generally not talked about in the clinical environment because there is uncertainty concerning what suffering is and there is no accepted physiological explanation. This could contribute to suffering being unaddressed, which could exacerbate the patient's suffering. Also, it is recognized that some nurses may engage in unhelpful behaviors in order to distance themselves from their patient's suffering. This might be attributed to a lack of personal coping strategies. This study attempted to begin addressing these gaps by specifically seeking out a sample of U.S. hospice nurses in order to ascertain how they identify and respond to their patients' suffering and personally coped and cared for themselves. Further, this study provides an inductive theory that will allow for future examination of nurse-patient interactions in the hospice setting.

Clinical Implications

Nurses in this study repeatedly emphasized the importance of the nurse-patient relationship as the context for identifying and responding to their patients' suffering. The nurses used their knowledge of the patient when choosing how and when to intervene in their patients' situations. Clinically, this indicates that consistency with the same nurse is important. The nurse needs flexibility to engage in patient interactions where there is time to enter into the small talk that leads to the larger, value-laden conversations that may affect subsequent care. These relational conversations rarely occur in the first couple of nurse-patient interactions highlighting the need for nurse continuity. This is even more important when a patient is admitted to hospice with a short projected length of stay (e.g., less than 7-10 days).

Even though the nurses did not ask about the meanings of experiences, they willingly engaged in conversations around meanings when the patient brought up the subject or the nurse needed to prepare a family for the impending death. Often times, this was done under the guise of helping the patient with "unfinished business." Expanding this to a routine practice of asking about meanings associated with symptom (or other life) experiences could provide direction to what the patient expects in regards to troubling areas. Asking about meanings may provide insight connecting the symptom experience to the patient situation, especially when medication response is unsatisfactory.

Providing the relational space and time to engage in value-laden, relational conversations requires an arduous compassion from the nurses because it demands insight into each individual's situation. Nurses need endorsement and guidance for how to cope with their varied thoughts and feelings. This sample of nurses knew their job required them to personally give of themselves. And sometimes, they needed help replenishing themselves through self-care activities. Frequently, they admitted this with a sense of personal failure. Almost as an aside, some would discuss the importance of needing others to touch or hug them with no expectation that they also reciprocate at that time. Due to the nature of hospice work, with time as a precious resource compelling the nurses to help patients reconcile relationships, some of the nurses missed being able to share "small talk" with other people about normal things. Clinical supervision and emotional support through mentoring and practical guidance need to be further developed to help nurses cope with the complexity of feelings that arise when caring for dying people.

Study participants often shared they gained insight from conversations they had with the patients' nursing assistants. The participants recognized that due to the time the assistants spent with the patients, listening to the patients and families share details of their lives, the assistants often had valuable information and perspectives about patients and their families. They often lamented that the assistants were not included in the IDT meetings. Including nursing assistants in the IDT meetings may provide a valuable personal perspective of how to mitigate patient/family suffering.

Recommendations for Professional Development

As part of every nursing school's curricula, nursing students are exposed to communication theories and to mental health theories. As the students progress in the curricula, they begin to have patient encounters and actually practice these foundational concepts—listening, responding empathically, asking clarifying questions. From these experiences, they learn to take a health history and to hear how the patient's story intertwines with their experience of health. For nurses entering into hospice nursing, additional education building on this foundation is needed. It is important for these nurses to be able to engage in relational communication that is very personal, value-laden, and invites the patient to open up and be at ease while disclosing very private information. The nurses need ways to gently guide a conversation in order to elicit meanings, spiritual beliefs, and past ways of coping. In addition to asking these questions, the nurses' need to gain a self-awareness of the non-verbal attributes they express when asking questions and responding to patient answers.

Recommendations for Future Research

A novel finding in this study is the recognition of suffering as a family affair. While this may be something unique to these particular participants, investigation is needed to ascertain whether suffering could be understood from a family perspective, how an individual's suffering would fit into this type of schema, and what aspects of suffering are present. Also, does this phenomenon occur in other patient populations (e.g., chronic illness) or is it something that is only found in families of dying patients? Recognizing that a family group may be suffering instead of individuals within a family may also open avenues for finding interventional strategies that are more congruent to the group need.

Findings from this study provide support for hospice nurses having an awareness and understanding of patient suffering. Consistent with previous studies, the hospice nurses did not have a defined knowledge base or prescriptive framework that indicated when and how to respond to various aspects of suffering. Yet, in their view, they were pretty adept at identifying and responding to their patients' suffering. It seems that they build on their basic nursing preparation and previous nursing skill sets adapting them to the hospice context and current patient situations. In addition to an underlying professional development occurring within the hospice practice setting, there seems to be some sort of reflective practice occurring. It is unclear how the nurse learns to assess his/her practice when entering a hospice environment or what exactly is transpiring. More research is needed in this area.

The sample for this study was hospice nurses because they are responsible for the daily management of their patients. When some of the participants in this study discussed what they would do if they were unsure if a patient was suffering or not, they indicated that they ask that patient's nursing assistant. The nurses explained that the assistants spent more time doing personal care and often spent this time engaging the patient in conversation. Through these conversations, the assistants often found out more information about what was currently important to the patient and how tension in family relationships currently affected the patient. More research is needed in this area to ascertain how the assistants could work with the nurses in order to mitigate the patient's suffering and how the assistants themselves cope.

Similarly, another area for further research is to consider the effect of the team as a whole has on mitigating patient suffering. Hospice work is done in the context of an interdisciplinary team layering a support network around the patient and family in order to support the patient's living well at EOL. Currently, it is unclear how (if) the disciplines (e.g., nursing, medical, counseling, pastoral) work together to alleviate suffering. Coming from a disciplinary perspective, each member may use the word “suffering” differently and subsequently, the team’s approach may be disjointed. Also, a strong personality, especially in the form of a respected physician, may influence what is said and unsaid according to the preferences of that individual’s biases or expectations.

This inductive theory offers an interpretive portrayal of the participants’ subjective experiences related to the meanings they gave to their patients’ suffering and how they translated these meanings into patterns of behavior used to respond to their patients’ suffering. As an interpretative portrayal of the process, neither is it an actual schematic of the process nor is it intended to guide nursing practice. However, it is intended to offer insights that will spark theory development in this area. In order to move the research in this clinical area forward, refinement of the theory is needed. By employing various qualitative and quantitative approaches in different populations and settings, relational linkages could be established and the theory’s boundaries tested, which could then be used to guide nursing practice.

DISCUSSION OF EVALUATIVE CRITERIA

Charmaz (2006) offers the following criteria for evaluating constructionist grounded theory studies: credibility, originality, resonance, and usefulness. Credibility refers to the capacity for belief. The data from this study came from 22 interviews, field notes, and analytic memos. While some of the informants were able to provide numerous insights and examples, other informants struggled to answer some of the interview questions. A few of the informants had an uncanny ability to describe in a step-by-step manner how they entered into a patient’s space and explain what they were assessing for and why it was important to them. At the other end of the spectrum, there were participants whose answers provided only scaffolding and big-picture views. These informants often provided direction for how to proceed with the next interview, which is consistent with constant comparative analysis. This is a beginning theory that needs further development using other samples to move the theory from a substantive theory to a formal theory. With time and more participants from multiple locations, the analysis could move towards a more hypothesis-generating stance. In the meantime, the findings and illustrative quotes provide the reader with information to form an independent assessment.

Originality refers to the freshness of insights. This is the first study examining how U.S. hospice nurses identify and respond to their patients' suffering. Previous studies identified various strategies that nurses used to respond to their patients' suffering. This study identified a process that the nurses use to identify and respond to their patients' suffering. Through utilization of this process, the nurses are deliberately choosing strategies to respond to specific aspects of the suffering they have identified.

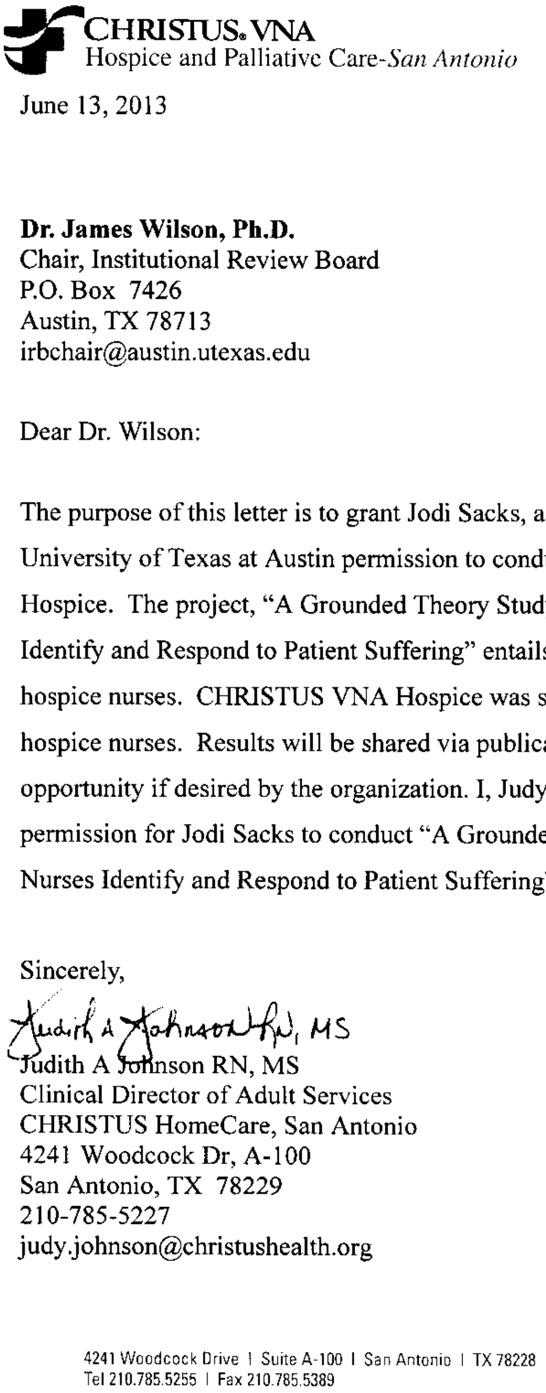
Resonance refers to an enriching fullness of the studied phenomenon. As the interviews proceeded, member-checking was used to verify previously identified concepts and also to explore various potential relationships between categories. Additionally, transcripts were shared and feedback obtained from the dissertation chairperson.

Usefulness refers to the theory's practical applicability. This study emphasized how important the nurse-patient relationship was to these participants and how they leveraged this relationship to identify and respond to their patients' suffering. However, this is an initial study time-bound and context bound to these particular participants. In order for different aspects of the theory to emerge and for the theory to become a more useful tool, the theory needs to be refined and tested in different EOL practice settings in order to evaluate the practical applicability. A more full evaluation of these criteria will only occur after dissemination of research findings that allows the findings to be scrutinized by a broader audience.

CONCLUSION

This chapter presented the main discussion of findings and implications of this research. The purpose of this study was to develop an inductive theory describing the process that U.S. hospice nurses use to identify and respond to their patients' suffering. Additionally, the study sought to describe the coping strategies that hospice nurses used when working with patients they considered to be suffering. Charmaz (2006) description of grounded theory methodology guided the study design and analysis. Participants identified and responded to their patients' suffering within the context of the nurse-patient relationship. They used a four-phase process to observe, assess issues, identify suffering, and intervene to ameliorate the suffering. Discussion of the findings showed many points of congruence with the current literature and some points of divergence. Implications for clinical practice and future research were also presented.

Appendix A: Site Letter



CHRISTUS® VNA
Hospice and Palliative Care-*San Antonio*

June 13, 2013

Dr. James Wilson, Ph.D.
Chair, Institutional Review Board
P.O. Box 7426
Austin, TX 78713
irbchair@austin.utexas.edu

Dear Dr. Wilson:

The purpose of this letter is to grant Jodi Sacks, a graduate student at the University of Texas at Austin permission to conduct research at CHRISTUS VNA Hospice. The project, "A Grounded Theory Study of How Hospice Nurses Identify and Respond to Patient Suffering" entails one-to-one interviews with hospice nurses. CHRISTUS VNA Hospice was selected because it employs hospice nurses. Results will be shared via publication and an in-service opportunity if desired by the organization. I, Judy Johnson, do hereby grant permission for Jodi Sacks to conduct "A Grounded Theory Study of How Hospice Nurses Identify and Respond to Patient Suffering" at CHRISTUS VNA Hospice.

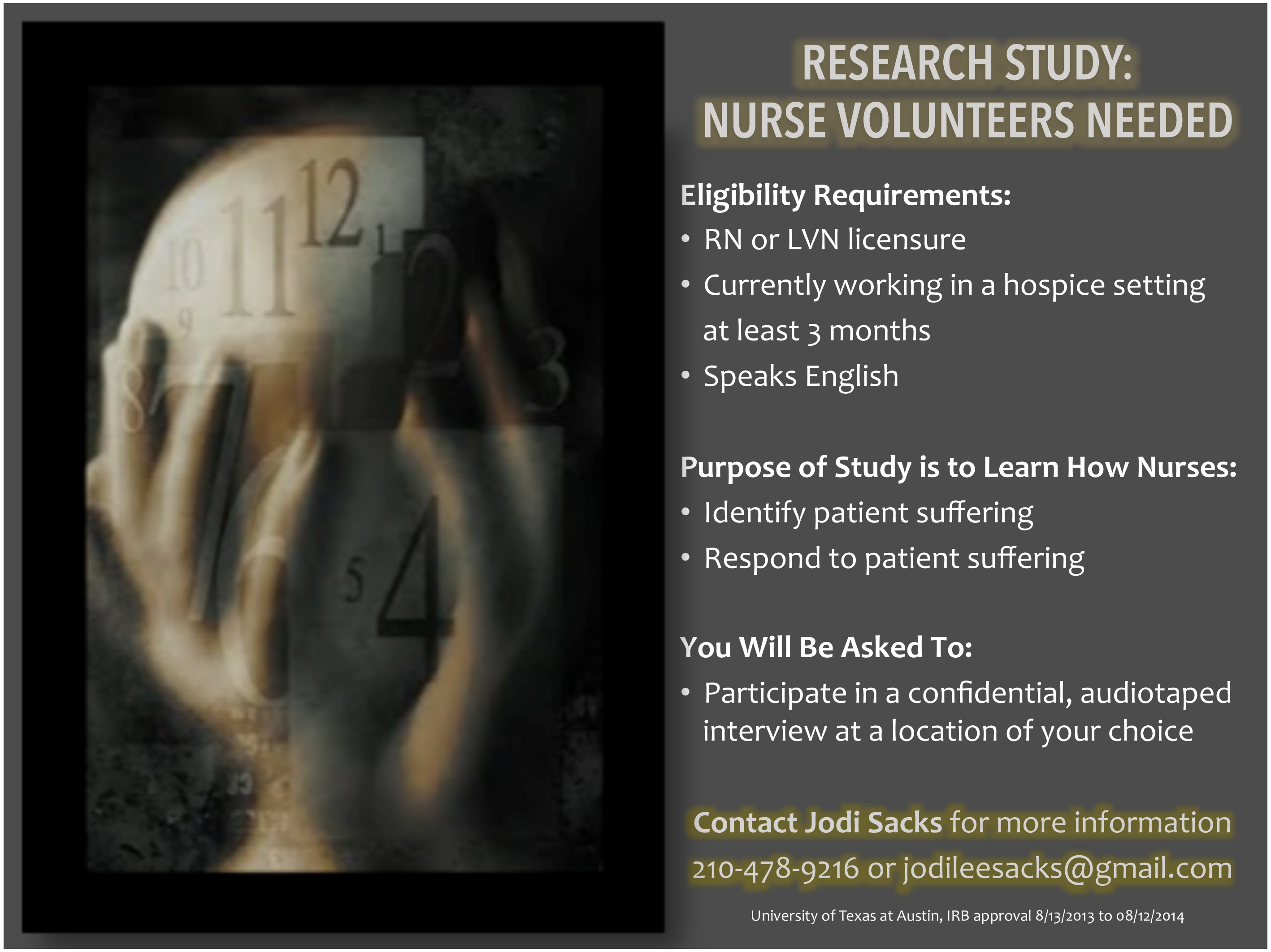
Sincerely,

Judith A Johnson RN, MS

Judith A Johnson RN, MS
Clinical Director of Adult Services
CHRISTUS HomeCare, San Antonio
4241 Woodcock Dr, A-100
San Antonio, TX 78229
210-785-5227
judy.johnson@christushealth.org

4241 Woodcock Drive | Suite A-100 | San Antonio | TX 78228
Tel 210.785.5255 | Fax 210.785.5389

Appendix B: Recruitment Flyer



RESEARCH STUDY:
NURSE VOLUNTEERS NEEDED

Eligibility Requirements:
- RN or LVN licensure
- Currently working in a hospice setting at least 3 months
- Speaks English

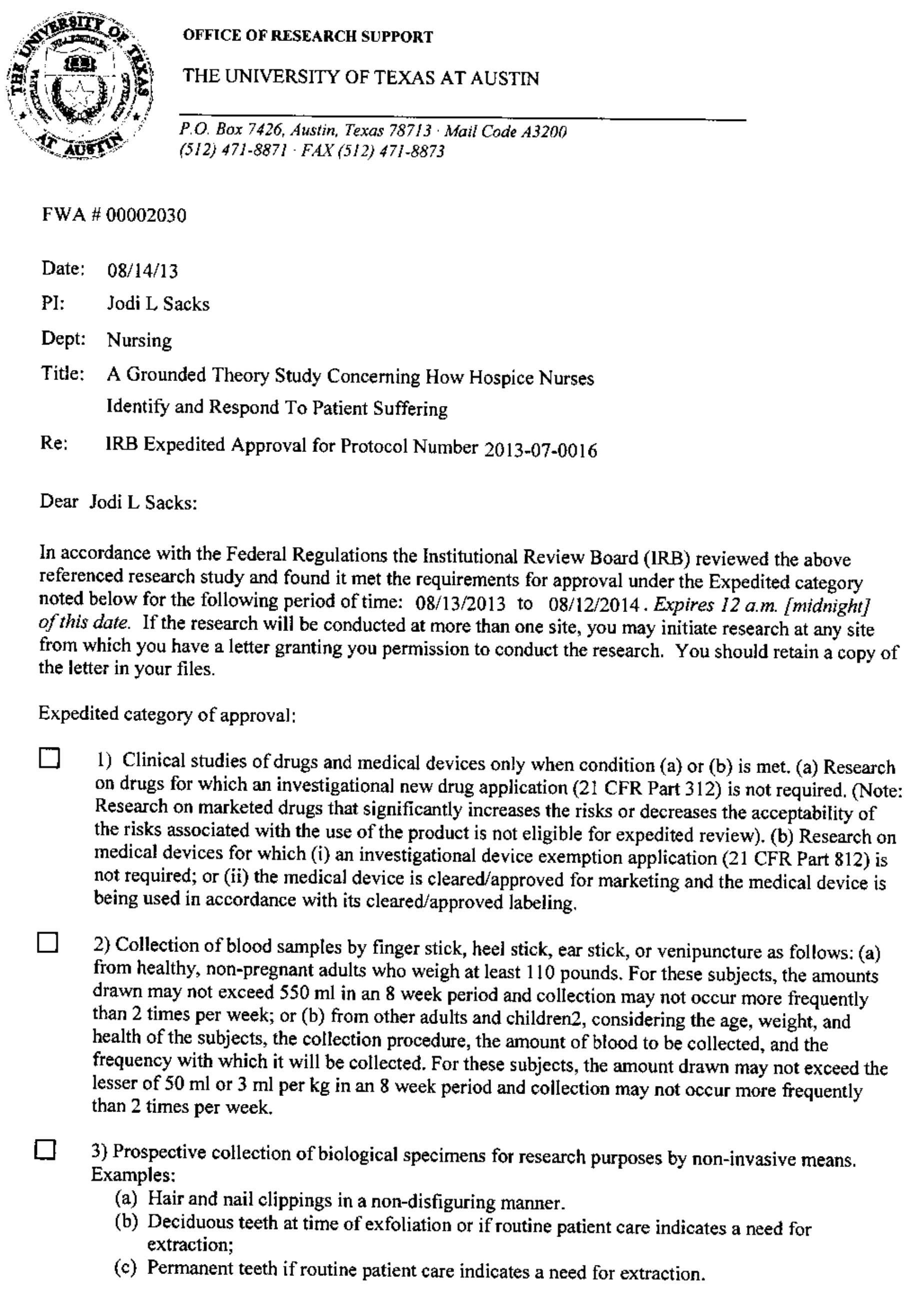
Purpose of Study is to Learn How Nurses:
- Identify patient suffering
- Respond to patient suffering

You Will Be Asked To:
- Participate in a confidential, audiotaped interview at a location of your choice

Contact Jodi Sacks for more information
210-478-9216 or jodileesacks@gmail.com

University of Texas at Austin, IRB approval 8/13/2013 to 08/12/2014

Appendix C: Institutional Review Board Approval Letter



OFFICE OF RESEARCH SUPPORT
THE UNIVERSITY OF TEXAS AT AUSTIN

P.O. Box 7426, Austin, Texas 78713 · Mail Code A3200
(512) 471-8871 · FAX (512) 471-8873

FWA # 00002030

Date: 08/14/13
PI: Jodi L Sacks
Dept: Nursing
Title: A Grounded Theory Study Concerning How Hospice Nurses Identify and Respond To Patient Suffering
Re: IRB Expedited Approval for Protocol Number 2013-07-0016

Dear Jodi L Sacks:

In accordance with the Federal Regulations the Institutional Review Board (IRB) reviewed the above referenced research study and found it met the requirements for approval under the Expedited category noted below for the following period of time: 08/13/2013 to 08/12/2014. *Expires 12 a.m. [midnight] of this date.* If the research will be conducted at more than one site, you may initiate research at any site from which you have a letter granting you permission to conduct the research. You should retain a copy of the letter in your files.

Expedited category of approval:

☐ 1) Clinical studies of drugs and medical devices only when condition (a) or (b) is met. (a) Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. (Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review). (b) Research on medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

☐ 2) Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows: (a) from healthy, non-pregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or (b) from other adults and children2, considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.

☐ 3) Prospective collection of biological specimens for research purposes by non-invasive means. Examples:
  (a) Hair and nail clippings in a non-disfiguring manner.
  (b) Deciduous teeth at time of exfoliation or if routine patient care indicates a need for extraction;
  (c) Permanent teeth if routine patient care indicates a need for extraction.

  - (d) Excreta and external secretions (including sweat).
  - (e) Uncannulated saliva collected either in an un-stimulated fashion or stimulated by chewing gumbase or wax or by applying a dilute citric solution to the tongue.
  - (f) Placenta removed at delivery.
  - (g) Amniotic fluid obtained at the time of rupture of the membrane prior to or during labor.
  - (h) Supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the process is accomplished in accordance with accepted prophylactic techniques.
  - (i) Mucosal and skin cells collected by buccal scraping or swab, skin swab, or mouth washings.
  - (j) Sputum collected after saline mist nebulization.

☐ 4) Collection of data through non-invasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications).
Examples:

  - (a) Physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy.
  - (b) Weighing or testing sensory acuity.
  - (c) Magnetic resonance imaging.
  - (d) Electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography.
  - (e) Moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.

☐ 5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).
Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.

☒ 6) Collection of data from voice, video, digital, or image recordings made for research purposes.

☒ 7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.
Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.

☒ Use the attached approved informed consent document(s).

☐ You have been granted a Waiver of Documentation of Consent according to 45 CFR 46.117 and/or 21 CFR 56.109(c)(1).

☐ You have been granted a Waiver of Informed Consent according to 45 CFR 46.116(d).

Responsibilities of the Principal Investigator:

1. Report immediately to the IRB any unanticipated problems.

2. Submit for review and approval by the IRB all modifications to the protocol or consent form(s). Ensure the proposed changes in the approved research are not applied without prior IRB review and approval, except when necessary to eliminate apparent immediate hazards to the subject. Changes in approved research implemented without IRB review and approval initiated to eliminate apparent immediate hazards to the subject must be promptly reported to the IRB, and will be reviewed under the unanticipated problems policy to determine whether the change was consistent with ensuring the subjects continued welfare.

3. Report any significant findings that become known in the course of the research that might affect the willingness of subjects to continue to participate.

4. Ensure that only persons formally approved by the IRB enroll subjects.

5. Use only a currently approved consent form, if applicable.
   Note: Approval periods are for 12 months or less.

6. Protect the confidentiality of all persons and personally identifiable data, and train your staff and collaborators on policies and procedures for ensuring the privacy and confidentiality of subjects and their information.

7. Submit a Continuing Review Application for continuing review by the IRB. Federal regulations require IRB review of on-going projects no less than once a year a reminder letter will be sent to you two months before your expiration date. If a reminder is not received from Office of Research Support (ORS) about your upcoming continuing review, it is still the primary responsibility of the Principal Investigator not to conduct research activities on or after the expiration date. The Continuing Review Application must be submitted, reviewed and approved, before the expiration date.

8. Upon completion of the research study, a Closure Report must be submitted to the ORS.

9. Include the IRB study number on all future correspondence relating to this protocol.

If you have any questions contact the ORS by phone at (512) 471-8871 or via e-mail at orsc@uts.cc.utexas.edu.

Sincerely,

James P. Wilson

James Wilson, Ph.D.
Institutional Review Board Chair

Appendix D: Consent for Participation in Research

IRB USE ONLY
Study Number: 2013-07-0016
Approval Date: 08/13/2013
Expires: 08/12/2014

Consent for Participation in Research

Title: Hospice Nurses Identifying and Responding to Patient Suffering

Introduction

The purpose of this form is to provide you information that may affect your decision as to whether or not to participate in this research study. The person performing the research will answer any of your questions. Read the information below and ask any questions you might have before deciding whether or not to take part. If you decide to be involved in this study, this form will be used to record your consent.

Purpose of the Study

You have been asked to participate in a research study about hospice nurses identify and respond to their patients' suffering. The purpose of this study is illuminate the process that hospice nurses use to identify patient suffering and then describe how nurses address this suffering. Additionally, this study seeks to describe nurses' personal coping strategies when working with suffering patients.

What will you to be asked to do?

If you agree to participate in this study, you will be asked to:

- Complete a short survey of demographic questions (e.g. nursing licensure, years experience)
- Participate in an interview at a location convenient to you. You may be asked to participate in a second interview in order to give your opinion about portions of the data analysis.

This study will take about 5 minutes to complete the demographic questions and approximately 60-75 minutes of time to complete the interview.

With your permission, the interview will be audio recorded.

What are the risks involved in this study?

The interview may involve risks that are currently unforeseeable. Possible risks associated with this study are experiencing emotional discomfort related to the experiences you share. However, this discomfort is probably no more than what you experience in your work setting.

What are the possible benefits of this study?

You will receive no direct benefit from participating in this study; however, some people believe that talking about an emotional experience is therapeutic and it may be a personal benefit of the study to you. Your participation may also benefit others by revealing areas of suffering that nurses are unaware of and may influence nurses to develop better ways to relieve suffering in their patients.

Do you have to participate?

No, your participation is voluntary. You may decide not to participate at all or, if you start the study, you may withdraw at any time. Withdrawal or refusing to participate will not affect your relationship with The University of Texas at Austin or your employer in anyway.

If you would like to participate, please sign this form prior to beginning the interview. You will receive a copy of this form.

Will there be any compensation?

You will not receive any type of payment participating in this study.

IRB USE ONLY
Study Number: 2013-07-0016
Approval Date: 08/13/2013
Expires: 08/12/2014

What are my confidentiality or privacy protections when participating in this research study?

This study is **confidential** and if you choose to participate in this study, you may choose to be audio recorded. Any audio recordings will be stored securely and only the research team will have access to the recordings. Recordings will be kept until accuracy of the written transcript is verified (approximately 7-10 days later) and then erased. Identifiable data will be destroyed after the study is complete. The data resulting from your participation may be used for future research or be made available to other researchers for research purposes not detailed within this consent form.

Whom to contact with questions about the study?

Prior, during or after your participation you can contact the researcher **Jodi Sacks** at **210-478-9216** or send an email to **jodileesacks@gmail.com.**

This study has been reviewed and approved by The University Institutional Review Board and the study number is **[STUDY NUMBER].**

Whom to contact with questions concerning your rights as a research participant?

For questions about your rights or any dissatisfaction with any part of this study, you can contact, anonymously if you wish, the Institutional Review Board by phone at (512) 471-8871 or email at orsc@uts.cc.utexas.edu.

Participation

If you agree to participate please sign this form prior to beginning the interview. It will be reviewed and you will receive a copy of it back at that time.

Signature

You have been informed about this study's purpose, procedures, possible benefits and risks, and you have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time. You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights.

For permission to audio record:

______ I agree to be **audio** recorded.
______ I do not want to be **audio** recorded.

______________________ Printed Name	______________ Phone Number
______________________ Signature	______________ Date

As a representative of this study, I have explained the purpose, procedures, benefits, and the risks involved in this research study.

____
Print Name of Person obtaining consent

____
Signature of Person obtaining consent

____
Date

Appendix E: Nurse Demographic Data Collection Sheet

Please place a check mark next to the line that best describes your licensure and answer the other questions:

Nurse Licensure:

- _____Licensed Vocational Nurse
- _____Registered Nurse
    - _____Diploma Prepared
    - _____Associate's Prepared
    - _____Bachelor's Prepared
    - _____Master's Prepared

Nursing Certifications (if any):

Male or Female:

Age at last birthday:

Years of nursing experience:

Healthcare areas worked as a nurse (ex: medical, occupational health, etc.):

Years of hospice nursing experience:

Number of hospices worked at:

Locations of previous hospices (city and state)

Types of hospices worked at (profit, non-profit, any with inpatient units):

Appendix F: Initial Interview Guide

Aim 1: To uncover what hospice nurses characterize as patient suffering.

RQ1.1: How do you describe suffering?

RQ1.2: How do you know when a patient is suffering?

RQ1.3: How do you think your perception of suffering differs from the patient's perception of suffering?

RQ1.4: How is the concept of suffering discussed by the health-care team in your setting?

Aim 2: To uncover the process hospice nurses use to respond to their patients who are suffering.

RQ2.1: What do you do for your patients who are suffering?

RQ2.2: What are some of the thoughts you have when you encounter a suffering patient?

RQ2.3: What are some of the emotions you have when you encounter a suffering patient?

RQ2.4: What are some of the interventions you do specifically to help a suffering patient?

RQ2.5: What are some of the actions you do when a patient is suffering patient? This could also be for the patient's family, the hospice team, or yourself.

Aim 3: To describe nurses' personal coping strategies used when working with patients they perceive as suffering:

> **RQ3.1**: What personal coping strategies do you use to help you care for suffering patients?
>
> **RQ3.2**: What are contextual (i.e, work setting, personal, family, religious) constraints or expectations that influence what you do?
>
> **RQ3.3**: What resources (i.e, work setting, personal, family, religious) are available to you or do you need when caring for suffering patients?

Appendix G: Community Resource Guide

If questions from the interview caused you distress and you would like to talk to someone about it, this list of resources may be a good place to find someone to listen. This list is not exhaustive.

Hotline

Center for Health Care Services Crisis Line	210-223-7233 / 1-800-316-9241

Counseling Providers (Adult)

Alamo Mental Health Group	210-614-8400
Baptist Child & Family Services	210-832-5000
BAMC Dept. of Social Work	210-916-3020
Catholic Charities	210-377-1133
Center for Family Relations	210-733-3349
Center for Health Care Services	210-731-1300
Creekview Recovery Center	210-280-0262
CHRISTUS Santa Rosa Health Care	210-704-3007
Community Counseling Services	210-434-1054
Our Lady of the Lake University Ecumenical Center for Religion & Health	210-616-0885
Elite Counseling	210-822-9493
Family Life Center	210-438-6411
Jewish Family Services of San Antonio	210-302-6920
Methodist Healthcare Ministries	210-922-6922
Nueva Vida Behavioral Health Center	210-616-0828
Presa Community Service Center	210-532-5295
San Antonio Family Endeavors Inc	210-431-6466
San Antonio Marriage & Family Counseling	210-501-0769
True Serenity Counseling Services	210-793-8395

Additional services could also be available through your Employee Assistance Program.

The Center for Health Care Services maintains a directory online, which allows a participant to search by zip code, distance, name, and type of service. It can be found at http://www.chcsdirectory.com.

Neither the interviewer, nor the University of Texas at Austin is responsible for the expenses of anyone who seeks these services.

References

Abraham, A., Kutner, J. S., & Beaty, B. (2006). Suffering at the end of life in the setting of low physical symptom distress. *Journal of Palliative Medicine, 9*, 658-665. doi: 10.1089/jpm.2006.9.658

Arman, M. (2007). Bearing witness: an existential position in caring. *Contemporary Nurse, 27*(1), 84-93. doi: 10.5555/conu.2007.27.1.84

Benzein, E. G., & Saveman, B. (2008). Health-promoting conversations about hope and suffering with couples in palliative care. *International Journal of Palliative Nursing, 14*(9), 439-445.

Berg, L., & Danielson, E. (2007). Patients' and nurses' experiences of the caring relationship in hospital: an aware striving for trust. *Scandinavian Journal of Caring Sciences, 21*(4), 500-506. doi: 10.1111/j.1471-6712.2007.00497.x

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Berkeley: University of California Press.

Boston, P. H., Bruce, A., & Schreiber, R. (2011). Existential Suffering in the Palliative Care Setting: An Integrated Literature Review. *Journal of Pain and Symptom Management, 41*(3), 604-618. doi: 10.1016/j.jpainsymman.2010.05.010

Boston, P. H., & Mount, B. M. (2006). The caregiver's perspective on existential and spiritual distress in palliative care. *Journal of Pain and Symptom Management, 32*(1), 13-26. doi: 10.1016/j.jpainsymman.2006.01.009

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*, 896-901. doi: 10.1089/jpm.2011.0442

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*(1), 1-9. doi: 10.1186/1472-6955-10-2

Centers for Disease Control and Prevention, & National Center for Health Statistics. (2012). Multiple Cause of Death 1999-2010 on CDC WONDER Online Database, released 2012. Accessed at http://wonder.cdc.gov/mcd-icd10.html on Apr 8, 2012.

Centers for Medicare and Medicaid Services. (2012). NHE Tables, 1960-2010. Baltimore, MD. Retrieved from: http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsHistorical.html

Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London, England: Sage.

Charon, J. M. (2010). *Symbolic Interactionism: An introduction, an interpretation, an integration*. Boston: Prentice Hall.

Chio, C.-C., Shih, F.-J., Chiou, J.-F., Lin, H.-W., Hsiao, F.-H., & Chen, Y.-T. (2007). The lived experiences of spiritual suffering and the healing process among Taiwanese patients with terminal cancer. *Journal of Clinical Nursing, 17*, 735-743. doi: 10.1111/j.1365-2702.2006.01854.x

Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Vissers, K. C., & van Weel, C. (2011). 'Unbearable suffering': A qualitative study on the perspectives of patients who request assistance in dying. *Journal of Medical Ethics: Journal of the Institute of Medical Ethics, 37*, 727-734. doi: 10.1136/jme.2011.045492

Eues, S. K. (2007). End-of-life care: improving quality of life at the end of life. *Professional Case Management, 12*(6), 339-344.

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. doi: 10.1111/j.1365-2702.2006.01620.x

Ferrell, B. R. (2006). Understanding the moral distress of nurses witnessing medically futile care. *Oncology Nursing Forum, 33*(5), 922-930. doi: 10.1188/06.onf.922-930

Ferrell, B. R., & Coyle, N. (2008). The nature of suffering and the goals of nursing. *Oncology Nursing Forum, 35*(2), 241-247. doi: 10.1188/08.onf.241-247

Georges, J. J., & Grypdonck, M. (2002). Moral problems experienced by nurses when caring for terminally ill people: a literature review. *Nursing Ethics, 9*(2), 155-178. doi: 10.1191/0969733002ne495oa

Georges, J. M. (2008). A praxis-based theory of suffering. *Communicating Nursing Research, 41*, 283-283.

Green, C. (2013). Philosophic reflections on the meaning of touch in nurse–patient interactions. *Nursing Philosophy, 14*(4), 242-253. doi: 10.1111/nup.12006

Gruiner, A., Mor, V., Weitzen, S., Truchil, R., Teno, J., & Roy, J. (2007). Where people die: A multilevel approach to understanding influences on site of death in America. *Medical Care Research and Review, 64*(4), 351-378. doi: 10.1177/1077558707301810

Hagren, B., Pettersen, I. M., Severinsson, E., Lutzen, K., & Clyne, N. (2001). The haemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease. *Journal of Advanced Nursing, 34*(2), 196-202.

Hospice and Palliative Nurses Association. (2012). HPNA Research Agenda 2012-2015. Pittsburgh, PA.

Kahn, D. L., & Steeves, R. H. (1986). The experience of suffering: conceptual clarification and theoretical definition. *Journal of Advanced Nursing, 11*(6), 623-631.

Kahn, D. L., & Steeves, R. H. (1994). Witneses to suffering: Nursing knowledge, voice, and vision. *Nursing Outlook, 42*(6), 260-264. doi: 10.1016/0029-6554(94)90046-9

Kahn, D. L., & Steeves, R. H. (1995). The significance of suffering in cancer care. *Seminars in Oncology Nursing, 11*(1), 9-16. doi: 10.1016/s0749-2081(95)80037-9

Kuuppelomaki, M., & Lauri, S. R. (1998). Cancer patients' reported experiences of suffering. *Cancer Nursing, 21*(5), 364-369.

Lambert, V. A., & Lambert, C. E. (2010). Editorial: philosophical basis for grounded theory research. *Pacific Rim International Journal of Nursing Research, 14*(4), 281-282.

Lorenz, K. A., Shugarman, L. R., & Lynn, J. (2006). Health care policy issues in end-of-life care. *Journal of Palliative Medicine, 9*(3), 731-748. doi: 10.1089/jpm.2006.9.731

Lynn, J. (2004). *Sick to death and not going to take it anymore: Reforming healthcare for the last years of life*. Berkeley: University of California Press.

Martins, C., & Basto, M. L. (2011). Relieving the suffering of end-of-life patients: A grounded theory study. *Journal of Hospice & Palliative Nursing, 13*, 161-171. doi: 10.1097/NJH.0b013e31820a95dd

Milliken, P. J., & Schreiber, R. S. (2001). Can You "Do" Grounded Theory Without Symbolic Interactionism? In R. S. Schreiber & P. N. Stern (Eds.), *Using Grounded Theory in Nursing*. New York: Springer Publishing Company.

Mok, E., Lau, K., Lam, W., Chan, L., Ng, J. S. C., & Chan, K. (2010). Healthcare professionals' perceptions of existential distress in patients with advanced cancer. *Journal of Advanced Nursing, 66*, 1510-1522. doi: 10.1111/j.1365-2648.2010.05330.x

Morita, T., Kawa, M., Honke, Y., Kohara, H., Maeyama, E., Kizawa, Y., . . . Uchitomi, Y. (2004). Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan. *Support Care Cancer, 12*(2), 137-140. doi: 10.1007/s00520-003-0561-6

Morse, J. M. (2000). Determining sample size. *Qualitative Health Research, 10*(1), 3-5. doi: 10.1177/104973200129118183

Morse, J. M. (2001). Toward a praxis theory of suffering. *Advances in Nursing Science, 24*(1), 47-59.

National Hospice and Palliative Care Organization. (2012). NHPCO facts and figures: Hospice care in America. Alexandria, VA. Retrieved from http://www.nhpco.org/i4a/pages/index.cfm?pageid=5994 on 8 October 2012.

National Institute of Nursing Research. (2011). Bringing Science to Life: NINR Strategic Plan. Bethesda, MD.

Newman, M. A., Sime, A. M., & Corcoran-Perry, S. A. (1991). The focus of the discipline of nursing. *Advances in Nursing Science, 14*(1), 1-6.

Nilmanat, K., Chailungka, P., Phungrassami, T., Promnoi, C., Tulathamkit, K., Noo-urai, P., & Phattaranavig, S. (2010). Living with suffering as voiced by Thai patients with terminal advanced cancer. *International Journal of Palliative Nursing, 16*, 393-399.

Rodgers, B. L., & Cowles, K. V. (1997). A conceptual foundation for human suffering in nursing care and research. *Journal of Advanced Nursing, 25*(5), 1048-1053. doi: 10.1046/j.1365-2648.1997.19970251048.x

Rydahl-Hansen, S. (2005). Hospitalized patients experienced suffering in life with incurable cancer. *Scandinavian Journal of Caring Sciences, 19*, 213-222. doi: 10.1111/j.1471-6712.2005.00335.x

Rydahl-Hansen, S., & Eriksen, T. R. (2009). How are verbal cues and signs of suffering expressed and acknowledged within palliative nursing? *Nordic Journal of Nursing Research & Clinical Studies, 29*(3), 42-46.

Sacks, J. L. (2013). Suffering at end of life: A systematic review of the literature. *Journal of Hospice & Palliative Nursing, 15*(5), 286-297. doi: 10.1097/NJH.0b013e3182811839

Sacks, J. L., & Nelson, J. P. (2007). A theory of nonphysical suffering and trust in hospice patients. *Qualitative Health Research, 17*, 675-689. doi: 10.1177/1049732306298524

Sand, L., & Strang, P. (2006). Existential loneliness in a palliative home care setting. *Journal of Palliative Medicine, 9*, 1376-1387.

Tapp, D. M. (2001). Conserving the vitality of suffering: addressing family constraints to illness conversations. *Nursing Inquiry, 8*(4), 254-263. doi: 10.1046/j.1440-1800.2001.00118.x

Thorup, C. B., Rundqvist, E., Roberts, C., & Delmar, C. (2012). Care as a matter of courage: vulnerability, suffering and ethical formation in nursing care. *Scandinavian Journal of Caring Sciences, 26*, 427-435. doi: 10.1111/j.1471-6712.2011.00944.x

U.S. Department of Health and Human Services, & Centers for Medicare and Medicaid Services. (2013). Medicare Hospice Benefits (CMS Product No. 02154). Baltimore, MD.

Wakefield, A. (2000). Nurses' responses to death and dying: a need for relentless self-care. *International Journal of Palliative Nursing, 6*(5), 245-251.

White, K., Wilkes, L., Cooper, K., & Barbato, M. (2004). The impact of unrelieved patient suffering on palliative care nurses. *International Journal of Palliative Nursing, 10*, 438-444.

Williams, B. R. (2004). Dying young, dying poor: a sociological examination of existential suffering among low-socioeconomic status patients. *Journal of Palliative Medicine, 7*(1), 27-37. doi: 10.1089/109662104322737223

Zhang, B., Wright, A. A., Huskamp, H. A., Nilsson, M. E., Maciejewski, M. L., Earle, C. C., . . . Prigerson, H. G. (2009). Health care costs in the last week of life: associations with end-of-life conversations. *Archives of Internal Medicine, 169*(5), 480-488. doi: 10.1001/archinternmed.2008.587

Zolnierek, C. D. (2014). An Integrative Review of Knowing the Patient. *Journal of Nursing Scholarship, 46*(1), 3-10. doi: 10.1111/jnu.12049