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HOW NURSES PERCEIVE PATIENT SUFFERING

BY

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THESIS

Submitted to the University of New Hampshire
In Partial Fulfillment of
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In
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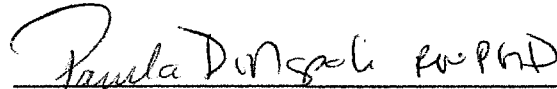
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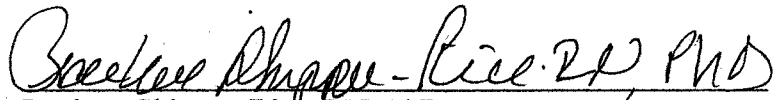
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DEDICATION

This thesis is dedicated to my husband, James, the love of my life and the rock of our family. His unwavering support and understanding for my fulfillment of a dream has made this possible.

To leave the world a bit better, whether by a healthy child, a garden patch, or a redeemed social condition; to know that even one life has breathed easier because you lived – that is to have succeeded.

Ralph Waldo Emerson

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ABSTRACT

HOW NURSES PERCEIVE PATIENT SUFFERING

By

Sandra J. Tanis

University of New Hampshire, December, 2008

Suffering is a complex and multidimensional experience that is individual in nature and deeply personal. Effecting all aspects of being – physical, psychological/emotional, sociocultural, spiritual – suffering may impact all dimensions of a patient’s life. The purpose of this study is to explore nurses’ perception of patients who suffer. The study aims to raise the level of awareness of patient suffering for nurses, and thereby serve as a basis for reflecting on the impact of their nursing care on the health of the individual and patient outcomes. A qualitative study explores how a group of eight nurses described suffering in their patients. Themes, which emerge from the narratives given by the nurses, include the effect of suffering on the four aspects of being, the inability to relieve suffering, the importance of presence, and listening to patient’s stories.

CHAPTER I

INTRODUCTION

Time is a precious commodity for a nurse and it is important to prioritize nursing care depending of what best meets the needs of the patient. This may mean being knowledgeable about patient insurance qualifications and coverage, location of care upon discharge from a facility, the impact of nursing care on patient outcomes and quality improvement. It may mean working with a greater number of chronically ill patients who are living longer, receiving more tests and procedures, and working with interdisciplinary team members to coordinate patient care plans. Sometimes a system's priority, such as high patient turnover, does not coincide with how nurses need to spend time. What is lacking in this landscape of health care is the availability of time to develop a caring relationship with a patient. Ferrell and Coyle (2008) questioned whether we have abandoned one of our primary responsibilities of relieving patient suffering. Newman (1994) referred to caring as the moral imperative of nursing, a value that drives us to address the needs and wants of those that suffer.

In a study of 1,059 caregivers who were asked to evaluate the end-of-life care of a loved one in a variety of settings, it was reported that health care providers did not provide adequate care of pain in 24%, dyspnea in 22% and emotional needs in 50% (Teno, Clarridge, Casey, Welch, Wetle & Shield, 2004). Whether a nurse is working with a dying patient, someone suffering from the ravages of cancer, a mother who has just had a miscarriage, an aging athlete with a knee replacement, or the elderly patient living alone with failure to thrive, various dimensions of suffering, observable or not, may be a part of their illness experience. For the purpose of this study, the context of suffering is not limited to death and dying or end-of-life care, but to the full spectrum of suffering experienced along the continuum of illness.

One who is suffering needs individual caring, confidence, guidance, dialogue and closeness (Fagerstrom, Eriksson, & Bergbom, 1998). These characteristics of attentiveness are driven by how a nurse perceives suffering. Webster's Collegiate Dictionary (Mish, 1991) stated that the word perceives means "to attain awareness or understanding of; to see, observe" (p.872). Synonyms associated with perceive are "realize, grasp, take in, find, identify, comprehend, detect, consider, and sense" (McKean, 2006, p. 605). The use of the word perceive raises the following questions. At what point during the nursing process does a nurse perceive a patient's suffering? Are there particular diagnostic skills or interventions that are necessary to assess suffering? Is time spent with the patient a factor in a nurse's ability to identify patient suffering? Must there be a certain quality to the nurse-patient relationship for suffering to be observed? A nurse may see a patient grimacing in physical pain, give the prescribed pain medication, and never give the situation another thought. Or a nurse may observe a sad and lonely patient who no longer eats or engages in conversation and wonders why he has changed, what has caused him to change, and what does he need in order to heal. A nurse's ability to be aware or understand a patient's suffering may be influenced by his/her professional and life experiences, education, beliefs and values.

Watson (2001) called for a reexamination of the grounding of our profession and posited a new script for nurses to engage in "different ways of being, doing, and knowing nursing" (p.80). The nurse is guided by relationships and meaning within a caring-healing paradigm, which focuses on being honest and real to self and patient, the act of being present, and the use of self-reflection in the nursing practice of caring for patients (Watson, 1997). The old script brushes over the essence of suffering, the wholeness of personhood, inner meaning, and self knowledge (Watson, 2001). Maybe this is not so much a new script, but a return to the basics of nursing and what calls us to do what we do. All care in some way serves to alleviate

suffering (Eifried, 1998; Eriksson, 1997; Lindholm & Eriksson, 1993), but the complex, intense, and cumulative effects of suffering requires a nurse who can take the time to acknowledge suffering and commit oneself to companionship with another human being. It may be that nurses take for granted the small ways in which they provide caring comfort and do not realize that they address the suffering needs of a patient. Indeed, the level of awareness of patient suffering by nurses needs to be enhanced or as Watson (2001) so aptly expressed “ a different consciousness and a mindful intentionality about their values, theories, and fundamental philosophy for caring-healing work “(p.80).

The purpose of this study is to explore nurses’ perception of patient suffering, providing greater insight into a caring and healing nursing practice. It aims to raise the level of awareness of patient suffering for nurses, and thereby serve as a basis for reflecting on the impact of their nursing care on the health of the individual and patient outcomes. It also aims to advance the knowledge base of nursing science by enhancing the advance nursing skills of connecting the mind, body, and spirit and provide new meaning to clinical care.

CHAPTER II

EARLY DEVELOPMENT OF RESEARCH IDEAS

Due to the complexity and lack of clarity in the use of the term suffering, I found it imperative to explore the concept of suffering. In this study a concept analysis was used to explicate the existing foundation of the concept of suffering to provide a clear meaning for use in research and clinical practice. Walker and Avant (1995) were chosen to provide structure to the concept analysis for this project. They recommended a process for concept analysis that included a literature review to compare and contrast definitions; assigning attributes, which appear over and over in the literature; identification of antecedents that occur prior to the concept; identification of consequences that occur as a result of the concept; and defining empirical indicators that indicate the existence or occurrence of the concept.

Webster's Collegiate Dictionary (Mish, 1991) defines suffering as "to endure death, pain, or distress; to sustain loss or damage; to be subject to disability or handicap; to submit to or be forced to endure" (p. 1179). Synonyms commonly associated with the word suffering are "hardship, misery, agony, anguish, hurt, sadness, heartbreak, sorrow, and grief" (McKean, 2006, p. 812). Einfried (1998) explained that contemporary views of suffering can vary from transient discomfort to anguish and despair. In this study the common understanding of suffering is applied to patients who may suffer in illness and experience physical pain, mental anguish, social isolation, or spiritual distress and look to health care providers for relief of their suffering and answers to their questions.

Attributes

The Latin roots of the words 'suffer' and 'patient' both mean 'to bear (Gadow, 1991; Rogers & Cowles, 1997). Gadow explained that the patient bears a burden and the sufferer

bears under a burden. This does not imply that all patients suffer, but an inherent quality of being a patient can be associated with suffering to some degree. A seminal figure on the topic of suffering, Cassel (1982) described suffering as being "experienced by persons, not merely bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity" (p. 639). The individual experience of suffering is recognized, not only in its uniqueness to the individual, but also in its wholeness (Gadow; Lindholm & Eriksson, 1993; Daneault, Lussier, Mongeau, Paille, Hudon, Dion, et al., 2004; Kahn & Steeves, 1986). Ferrell and Coyle (2008) referred to "the deep and profound experience of suffering by the individual" (p.5). Cassel emphasized the importance of person and not merely body, which reinforces the whole nature of suffering to include all aspects of being - physical, psychological, sociocultural, and spiritual. A sense of challenge is defined in terms of a struggle of the whole person by Cassell (1999) and Lindholm and Eriksson. For some, meaning in suffering is fear of death or being vulnerable (Daneault, 2004). For others, the challenge of suffering is experienced in the threat to personal integrity and continued existence (Ferrell & Coyle).

Even though pain and suffering are closely linked and often thought to be one and the same, Gadow (1991) wrote that in order to understand suffering, one must differentiate it from pain. Suffering cannot be fixed with a pill in the way pain can be treated with medications. Pain may be related to physical symptoms such as fatigue and nausea (Ferrell & Rhiner, 1991), constipation, edema, neuropathic pain (Ferrell, Levy, & Paice, 2008), and dyspnea (Teno et al., 2004). Pain and suffering may be mutually exclusive of one another, such that you may have either one without the other (Kahn & Steeves, 1986; Morse, 2001). In reference to the individual nature of suffering, each distinct person can perceive the same level of pain in different ways and intensity, which may or may not culminate in different degrees of suffering

(Gadow). Pain is what the patient says it is and to ignore, doubt, or belittle a patient's pain can lead to suffering (Cassel). The key to understanding the difference between pain and suffering is Cassel's (1982) appraisal that suffering may be caused by pain, but is not defined by it. Once again, this places suffering within the realm of meaning for the patient, because the patient is the only one who can truly define the experience. By defining the experience of suffering, the patient gives meaning to the experience of suffering in the form of a challenge struggle, fear or threat. For the purpose of this study, the use of the word suffer implies the meaning that the patient gives to the symptom being experienced (Cassell, 1999; Eifried, 1998; Gadow, 1991).

Antecedents

Conditions that may precede suffering may include being subjected to violence, deprived and overwhelmed, and living in apprehension (Daneault et al., 2004). Violence can be represented by assault of illness upon the patient; the constant roller coaster ride of remission and relapses; or the intrusion of the entire health care system upon the life of the patient – physician visits, hospital stays, medications, medical insurance – resulting in overwhelming vulnerability (Daneault et al., 2004). It has long been recognized that nursing and medicine can be responsible for inflicting pain upon the patient. Ferrell and Coyle (2008) visualized pain infliction and the inability to relieve pain as a form of violence against the patient.

A source of suffering for patients is the sense of being deprived of well-being (Daneault et al., 2008) and overwhelmed with losses that occur. The experience of losses can include autonomy, control, goals, social identity, hope, and dignity (Ferrell & Coyle, 2008). The loss of interpersonal relatedness expresses the communal nature of suffering (Gadow, 1991). Suffering is often related to an interpersonal relationship with other human beings (Gadow, 1991). This does not diminish the individual nature of suffering, but adds to the complexity of the experience by exposing suffering and what it means for the individual. When a parent loses

a child, a husband loses a wife, the relationships have been long established and the suffering is great, but in the realm of nursing, it is the quality of the relationship between the nurse and the patient that is imperative to the relief of suffering (Eifried, 1998; Eriksson, 1997; Lindholm & Eriksson, 1993; Mok & Chiu, 2004; Watson, 2001; Watson & Foster, 2003). Therefore, a meaningful relationship between a nurse and patient can promote an environment where suffering may be alleviated. Kahn and Steeves (1986) spoke of a loss of identity, which gives importance to continued existence. This can include change in body image; job loss changing one's social identity; or isolation as one withdraws from family and friends. Morse (2001) synthesized social suffering as effects experienced through war, famine, and societal violence, which lead to a loss of meaning of self. Chochinov (2006) posited that the loss of dignity is the most critical component of suffering for a patient and described it as a loss of generativity and how one will be remembered. The question 'why?' surfaces in discussions as patients try to understand that for which there are no answers (Ferrell & Coyle), augmenting and intensifying all domains of the personal experience.

Living in apprehension produces a constant source of fear, uncertainty, and dread of the unknown that may lead to suffering (Daneault et al., 2004). Fear of death and feeling vulnerable are as potent to the suffering patient as any physical symptom of pain (Daneault et al., 2004). Ferrell and Coyle (2008) spoke of the roller coaster ride between hope and hopelessness in critical care. Morse (2001) highlighted patient experiences with suffering that included waiting for test results in which one fears the worst, yet hopes for the best; the total unpredictability of each day; and the uncertainty of the future.

Consequences

There are two main consequences of suffering. The first is a continued life of suffering in silence with a disconnect to life as it once was (Morse, 2001; Rehnsfeldt & Eriksson, 2004).

The second is the human potential to transcend the experience of suffering and restore some semblance of meaning to life. Moving beyond the suffering experience can provide healing by living life outside oneself, living life more deeply (Morse, 2001). Newman (1994) guided the sufferer to embrace the experience, letting go of all that has been feared, and viewing oneself as part of a larger whole. A world of meaning can be created out of suffering, allowing a new sense of self to emerge (Gadow, 1991; Byock, 1994). Moving above and beyond suffering, referred to as transcendence, offers the sufferer a chance to restore their personhood or for a new self to emerge (Byock; Cassel, 1982; Newman). A sense of surrendering to the experience and allowing a new self to be released and transformed is reported by patients who have suffered (Byock).

Empirical Indicators

Suffering is not always obvious and requires skill in observing and knowing the patient, being attentive to change in behavior, mood or posture, and bearing witness to that which some may dismiss. The emotional release of suffering, when it can no longer be endured, may include stooped posture or collapse on the floor, sobbing, crying, weeping, moaning, and talking to whomever will listen (Morse, 2001). The unique personalities of individuals can also portray similar expressions of suffering. Lindholm and Eriksson (1993) differentiated the direct patient that expresses his hurts, the aggressive patient that screams and is abusive, the isolated patient that does not make contact, the defensive patient that denies needs, and the actor who expresses suffering in non-verbal ways. This illustrates the case and point of knowing your patient, their behavior, how they express themselves, what language or lack of language they use, and to discover the world in which they suffer and what meaning it holds for them.

In summary, what is clear about the concept of suffering is the individual nature of the experience, which holds personal meaning for the individual, and the challenges and struggles which threaten not only the total personhood, but also impacts the lives of all who are emotionally tied to the individual. The ability to recognize the cues of suffering in all realms of the patient and not just physical pain and what is observable, is critical in guiding nurses to better understand and deal with the personal nature of patient suffering.

CHAPTER III

LITERATURE REVIEW

Following the concept analysis, a review of literature was conducted. Literature from 1982 to 2008 was searched in Academic Search Premier and CINAHL databases and other publications, i.e. books, using key words of pain, patient suffering, caring science, qualitative description and refined with the words human suffering and nurse-patient relationship. An abundance of articles was found and from these articles, primary sources were researched, including web-cites. 66 sources were considered with 27 being rejected due to the following exclusion criteria: too specific and not general enough to encompass a broad range of patient suffering, patient suffering lacked definition, purpose of the study was unclear, or the research process was not followed. Inclusion criteria for sources used for the review were emphasis on patient suffering, nursing perspective of suffering, clear statement of purpose, and seminal authors on the topic of patient suffering. The literature review includes one meta-analysis, one controlled trial, and seven commentaries/opinions. The commentaries/opinions were all written by seminal figures on the topic of suffering or human caring. To give the researcher the broadest base of knowledge with which to conduct this project, suffering was reviewed within the context of numerous disciplines, including bioethics, caring science, critical care, health services, medicine, mental health, nursing ethics, religion, and social science. The literature review consists of three sections. The first section connects caring and suffering to better understand the relationship for nursing. The second section illustrates the aspects of being exemplified in the definition of suffering and the interaction between them. The final section highlights the most prevalent themes found in the literature pertaining to the nursing role in working with patients who suffer.

Connecting Caring and Suffering

In 1988 Watson(1997) revisited her Theory of Human Caring and called for different ways of being a nurse, grounded in relationships and meaning with respect to living and dying within a caring-healing paradigm. This caring-healing paradigm focuses on transpersonal caring, in which the nurse integrates authenticity of being, the act of being present, and the use of self-reflection into the nursing practice of caring for patients (Watson, 1997). Watson explained these three characteristics as the ability of the nurse to be more honest and real to self and patient, to be more present in the act of caring, and to have more knowledge of self (Watson, 2001). Concurrently, Eriksson developed the Theory of Caring, which stated “caring is based on the original view of the patient as a suffering human being (Eriksson, 1997, p. 11). In her theory, Eriksson differentiates between nursing care as the nursing process and caring nursing, which describes the inner core of a nurse that allows for good and individualized care (Eriksson, 1997). Together they establish a communion between the suffering patient and nurse (Eriksson, 1997). A discussion within the nursing community ensued throughout the 1990’s, highlighting the connection between and the imperative need to integrate caring and the alleviation of suffering into the nursing process (Eifried, 1998; Ferrell & Rhiner, 1991; Lindholm & Eriksson, 1993; Newman, 1994). Fifteen years ago Lindholm and Eriksson stated “The alleviation of suffering has always been the cornerstone of caring” (p. 1354). This is a powerful message to nurses today who question how they are to alleviate suffering in their patients.

Findings from a pivotal study of 9,105 adults in 1995 called The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments , or SUPPORT, served to strengthen the importance of this discussion (Connor, Dawson, Desbiens, Fulkerson, Goldman, & Knaus et al., 1995). The outcomes of this study demonstrated shortcomings in the delivery

of care to seriously ill hospitalized patients, including failure to adequately relieve pain and suffering. In summary, Lynn (1997), co-director of the project, addressed the complexity of the problem and noted changes in social myths, professional values, and community priorities that would have to be part of the solution to the shortcomings. When one considers the wholeness of personhood impacted by suffering, there is tremendous insight, education, and experience to be accumulated within a caring-healing paradigm necessary to acknowledge, assess, and implement care for patients who suffer.

Aspects of Being

The four aspects of being are the physical, psychological/emotional, sociocultural, and spiritual/existential and each one may be impacted by suffering (Ferrell & Coyle, 2008). To understand how suffering impacts the four aspects of being, one must look beyond suffering as transient discomfort, anguish, or despair (Eifried, 1998). As stated previously, for the purpose of this study, the use of the word suffering implies meaning that the patient gives to the experience of pain (Cassell, 1999; Eifried, 1998; Gadow, 1991). Gadow (1991) explained that one must differentiate between pain and suffering and added to this differentiation, Kahn and Steeves (1986) offered the following definition.

Suffering is not only distinct from pain, but it also represents another level of individual response...consider an individual in pain – the perception of that pain is usually grounded in some neurological or physical cause. The individual's particular experience of pain results as that perception is mediated by individual and cultural factors. Suffering, on the other hand, is not grounded in the same cause or stimuli but derives from the individual's evaluation of the significance or meaning of the pain experience. (p. 625).

Therefore, the patient experiences physical pain resulting in suffering, but the pain itself does not define the suffering.

Byock (1994) questioned the continued association of suffering with physical pain by most clinicians. Even though the experience of suffering may be initiated or exacerbated by physical pain, there is ample support in the literature for all four aspects of being to be effected.

Pain effects the overall quality of life and proves to be problematic in 50 to 80 percent of cancer patients (Ferrell & Rhiner, 1991). In a study of patients and nursing care in a trauma center, Proctor, Morse and Khonsari (1996) discussed the effectiveness of comfort talk by nurses with patients whose pain, due to injury and necessary medical procedures, was so intolerable, the patient sometimes lost control. The objective observation of patients moaning, whimpering, crying, and screaming (Proctor et al.) as an expression of suffering is at the opposite end of the spectrum of those who project mute suffering, in which case, one must simply ask, "Are you suffering?" (Cassell, 1999).

The impact of suffering on the psychological/emotional aspect of being is commonly expressed in terms of distress, experienced along a continuum from sadness to panic (Benner, 2004; Cassell, 1999; Kelly et al. 2006). Patient expression of psychological suffering can be observed through signs of worry, impatience, and uncertainty (Eriksson, 1997), suspicion and fear (Benner), depression and anxiety (Kelly et al.), feeling trapped, helpless, inability to cope, and restless (Ferrell & Coyle, 2008), and at the extreme, cognitive impairment and delirium (Ferrell & Coyle; Kelly et al.). In a study of psychological distress in palliative care patients, Kelly et al. highlighted measurement tools for depression, anxiety, and delirium. This quantitative approach provides a balance in recognizing feelings and emotions as a result of the impact of suffering, which can ultimately lead to better patient outcome.

Cassel (1982) raised the question whether depression is not simply unrelieved suffering. Many times depression follows the death of family and friends, loss of job, chronic illness, or damage to self-esteem and person. Patients who appear to have recovered from an illness may not function in the same previous capacity, and feeling threatened and vulnerable, are unable to work, resume normal sexual function, or participate in activities with friends (Cassel). Unless

this is examined, patients may assume this is a normal course of events along their journey of healing, leading to depression and resulting in suffering.

Even though the individual nature of suffering has been identified, the sociocultural aspect of suffering experienced by patients underscores the communal nature of suffering and the threat to one's self through loss. Various studies emphasize different losses experienced by the sufferer, including loss of respect in being treated as a body and not a person (Cassel, 1982; Chochinov, Hack, McClement, Kristhanson & Harlos, 2002; Eriksson, 1997); being a burden to family and loved ones through continued dependence for care and decision making (Chochinov et al.; Byock, 1994); being too exhausted to engage with people (Byock, 2002; Puchalski, 2002); and loss of social identity through job loss and role disintegration within a family or community (Chochinov et al.). Gadow (1991) stated "While pain may be a private physical experience of the individual, suffering is related to the interpersonal meaning we create with one another" (p.104).

We can experience pain by ourselves, but the degree and extent of suffering may be determined by the nature of involvement of others. A child may be told by a nurse that a shot will not hurt, but the child will suffer, nonetheless, when he/she cries out in pain, because the nurse has compromised the nurse-patient relationship by not being honest with the patient (Gadow, 1991). When a negative reaction to a patient's decision by a loved one creates chaos in a family, the sufferer loses all meaning in suffering, because as Gadow explained " If the other person reacts in a way that places the pain outside the interpersonal sphere of meaning, then the pain becomes suffering" (p. 104). In this example, not only does the patient suffer, but the family suffers as well. Watson (1988) in her *Theory of Human Caring* and Eriksson (1992) in her *Theory of Cariatative Caring* both serve to transcend the communal nature of suffering by placing the caring nurse within the suffering realm of the patient. The patient's suffering is the

focus of care, however, the needs of the suffering family must also be addressed in a way that they, too, can understand what suffering means to the patient. It is at this point that caring by the nurse can reach full understanding of the patient's world and help to facilitate meaning in the face of chaos to the experience of suffering by the patient.

Religion, spirituality and existentialism share a common ground of providing the individual with hope and a sense of purpose and meaning in life (Chochinov, 2006). For the purpose of this project, the term spirituality will be used to refer to all three aspects. Much of the research on how suffering can effect the state of one's spirituality, suggests that spiritual well-being contributes to the health of many people and provides strength and a way to cope in the face of illness, loss, and death (Byock, 2002; Pulchalski, 2002). Kelly et al. (2006) demonstrated in a study of 160 hospitalized cancer patients that there is a negative correlation between spiritual well-being and the desire for death, meaning that spiritual well-being may shield one from end-of-life anguish. Several studies on suffering, support the lack of meaning and purpose as the main component of spiritual suffering (Cassel, 1982; Ferrell & Coyle, 2008; Gadow, 1991; Eifried, 1998). This may be an explanation as to the concentration of literature on the impact of suffering on the spiritual aspect of being within the dimensions of death, dying, and end-of-life care. It is at those times along the continuum of illness that a patient may question the meaning of life and experience hopelessness, loss of dignity, and the will to live (Chochinov, 2006).

Spiritual suffering is not identified on the basis of symptoms, but through behaviors, which may be uncharacteristic of the individual (Chochinov, 2006). These behaviors include patients who continually pursue new treatments without shown benefit, patients who hunger to escape their life situation, and patients who request increasing amounts of analgesics and sedatives with no proven benefit. Behaviors involving rituals that are important to the patient during

illness are important to assess. Spirituality and culture-related beliefs offer rituals that not only provide solace for the patient during suffering, but also enable the nurse to explore what meaning this experience may hold for the patient (Ferrell & Coyle, 2008; Ferrell, Levy, & Paice, 2008). Assessing the need for ritual early on in the caring process is important in having the components in place at a time when they are needed most. Ferrell et al. acknowledged that opportunities to assess spiritual and cultural beliefs and rituals are often overlooked. Spiritual care can be implemented through the use of a spiritual assessment tool (Lo, Ruston, Kates, Arnold, Cohen, Faber-Langendoen, et al., 2002) or a referral made to a hospital chaplain or spiritual counselor. Sometimes it might be necessary to discuss with family members if there are any after-death rituals important to the family and patient (Ferrell et al.).

To endure suffering may make life bearable and failure to endure may make life unbearable (Cassell, 1999). Rehnfeldt and Eriksson (2004) argued that when suffering is bearable for a patient, there is a constant flow between extremes of hope and hopelessness, meaning and meaninglessness. Morse (2001) conceptualized this as blocking of emotional responses so that patients can deal with day-to-day issues. For some patients there may be a robotic quality of function with mask-like expressions, as the patient focuses on the present and at the same time, develops coping strategies.

Failure to endure can be a result of chronic pain, trauma, or procedural pain, according to Cassell (1999), which in turn makes life unbearable. Unbearable suffering is a release of emotional control in which there are observable signs of sadness and bodily expressions of failure (Morse). Although the patient may speak of death and dying, Rehnfeldt and Eriksson associated this as a turning point, because the patient has reached an understanding, a sense of resolution with the unbearable and the need to express emotion of the struggle being

experienced. At this point the question “Why?” may be asked, resolution may be possible, and the experience of suffering can take on new meaning for the patient.

It is important in the attempt to alleviate suffering to acknowledge the interaction of one aspect of being with another or the interaction of all four aspects of being - physical, psychological/emotional, sociocultural, and spiritual/existential. Interaction also serves to underscore the interconnectedness of the mind, body, and spirit. This theme is supported in the literature primarily in the studies of palliative care, where the primary focus is improvement in the quality of life, by providing comfort and preserving dignity (Chochinov, 2006). Within an advanced cancer setting, Ferrell et al. (2008) identified the need for involvement of the physician, nurse, social worker, and hospital chaplain to address the complex needs of a woman suffering from symptoms of ovarian cancer with bowel obstruction and voicing hope for another month with her grandchildren. Priority is given to controlling the physical pain, but alleviating suffering can only be achieved if the other components of being - psychological, sociocultural, and spiritual – are examined and managed.

The interaction of the psychological and physical aspects of being impacted by suffering is seen in the following examples. Depression, anxiety, and delirium are psychological symptoms commonly found in palliative care and delineated in a study by Kelly et al. (2006). Depression may be a manifestation of psychological distress leading to physical symptoms of fatigue, poor concentration, sleep disturbance and appetite and weight change. Anxiety may be experienced with physical symptoms of cardiovascular disease or may exacerbate the existing condition of dyspnea in lung cancer patients. Delirium is usually recognized as an acute change in the state of consciousness, but can also be manifested in agitated behavior; emotional disturbances of depression and irritability; and loss of cognitive acuity. The most comprehensive and useful example of the interaction of the aspects of being as a result of suffering is the symptom of

fatigue as experienced by cancer patients receiving chemotherapy (Figure 1). The initial trigger is cancer chemotherapy received by the patient; the immediate effect is the physiologic effects of the chemotherapy on the patient; the patient symptom is fatigue; and the impact of fatigue on the physical, psychological, social and spiritual dimensions of the patient results in suffering (Ferrell & Coyle, 2008). The arrows go in both directions, indicating reciprocity, which adds to the dimension of interaction.

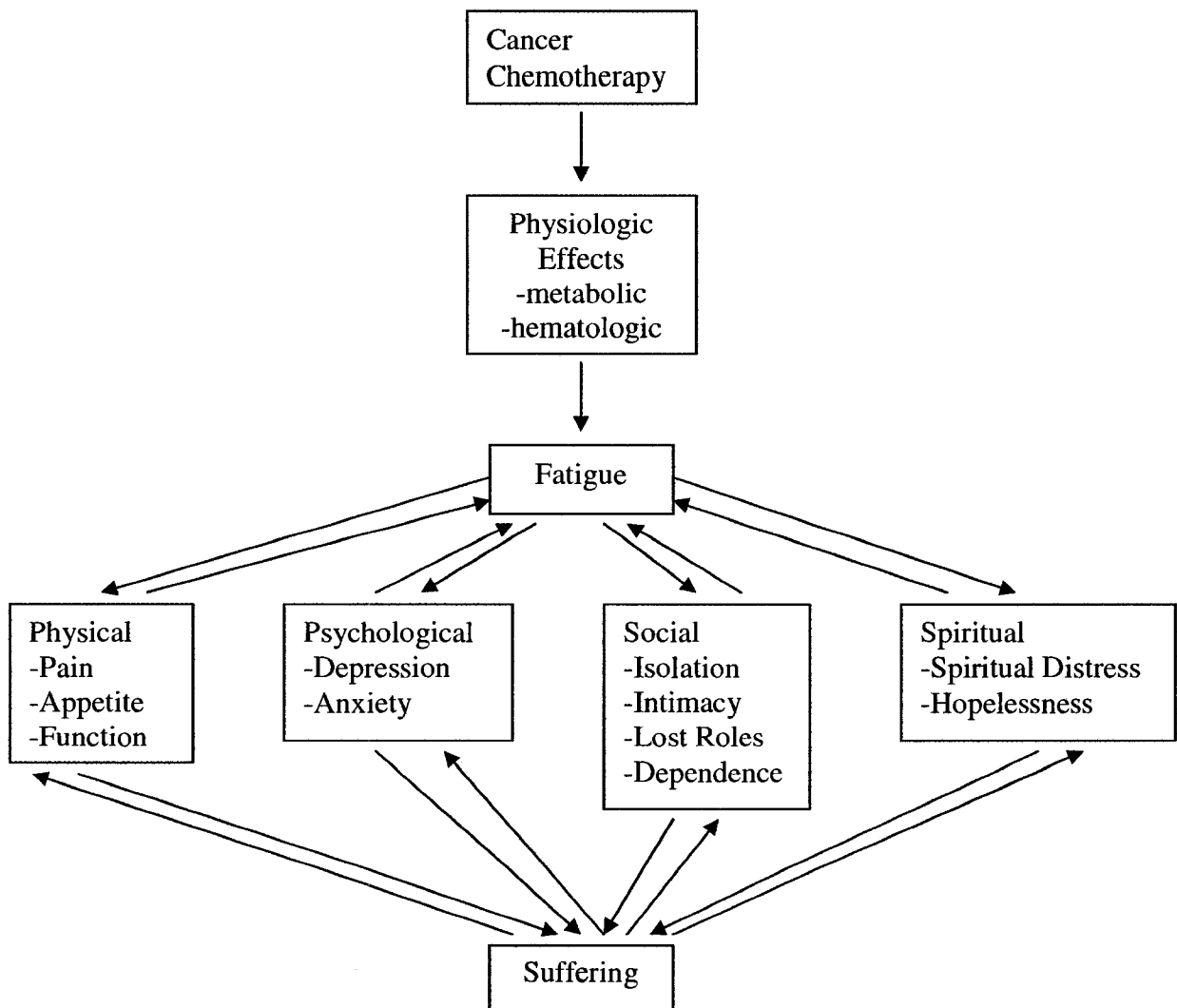


Figure 1. The Process of Fatigue Impacting Quality of Life (Ferrell & Coyle, 2008, p. 13)

The cumulative effect on the four dimensions of the patient results in greater suffering. Figure 1 also illustrates the differences in suffering that may be experienced by an individual such that one's physical and social dimensions may be impacted, but not the psychological and spiritual dimensions. However, given the continuum along which many of these dimensions are experienced and the interactive quality, it is difficult to imagine experiencing the impact of one without the other dimensions also being effected.

Loss of dignity is a particularly fluid concept and can be experienced in all four aspects of being, creating a chain of events. Expressions of hopelessness and loss of meaning in life from the spiritual dimension, loss of intimacy and autonomy from the sociocultural dimension, and expressions of depression from the psychological dimension may exacerbate physical pain being experienced by the patient, compounding the suffering. As the physical pain becomes worse, the symptoms from other aspects of being are compounded, creating an exacerbation of symptoms that may be difficult to identify and treat.

Morse and Johnson (1991) recognized the interaction of the physical pain, emotional discomfort, and social distress. Using human behavior as a basis, Morse and Johnson (1991) developed an Illness-Constellation Model in which suffering is a prime variable in the illness process. The goal of this model was to minimize suffering and attain comfort for the individual. The model included the following points: illness does not necessarily mean that disease is present; illness is an experience of an individual that reverberates to all significant others; minimizing suffering is directed from a holistic perspective of physical pain, psychological pain and social distress (Morse & Johnson). Morse and Johnson defined suffering as a "comprehensive concept incorporating the experience of both acute and chronic pain, the strain of trying to endure, the alienation of forced exclusion from everyday life, the

shock of institutionalization, and the uncertainty of anticipating the ramifications of the illness” (p.338).

Prevalent Themes in Working with Patient Suffering

Just as the literature differentiates physical pain and suffering, a realistic goal in working with patients who suffer should be the alleviation or lessening of suffering, rather than the elimination (Lindholm & Eriksson, 1993). The physical pain can be eliminated with medication, but the human response to suffering, encompassing a struggle, may only be diminished by reducing the patient’s vulnerability. Nurses working in palliative care focus on comfort and quality of life as defined by the patient (Pavlish & Ceronky, 2007). By so doing, suffering may be alleviated and sometimes even eliminated, but the emphasis is on the needs and wants of the patient, which may or may not include continued curative treatments already causing pain and suffering to the patient.

Contextual analysis or the context in which a patient suffers is an important consideration for nurses working to alleviate suffering. Gadow (1991) emphasized the importance of understanding what meaning suffering holds for the individual. This is further explained by Cassel (1982) in delineating the characteristics of a person which may effect how and to what degree a patient suffers, including personality and character, personal past, life experiences within the realm of illness, connection to family, and cultural background. Consider the implications of working with a patient suffering from rheumatoid arthritis whose passion is playing the piano; a woman suffering from ovarian cancer whose dream is to have a child; a father of three young children who is told that he has metastatic lung cancer with only a short time to live; or a young adult who has been separated from family and living on his/her own for two years and becomes paralyzed in a skiing accident. Knowing who the person is and what

is important to him/her are essential components in developing a care plan for patients who suffer.

The characteristics mentioned above may be revealed through story telling by the patient, and as revealed in the interview process of this project, by nurses as well. Stories provide “contextual grounding” (Heliker, 1999, p.515) through which the nurse may discover common themes and a new understanding of this experience for the individual. For nurses, listening to a story also provides narrative knowledge of the meaning and significance of a patient’s situation, which can lead to a closer relationship between the patient and nurse (Charon (2001)). Narrative knowledge may include words, gestures, physical findings, silence, fears, hopes, and what is not revealed (Charon, 2001). Crucial information can be garnered from which a care plan can be developed by asking the patient to tell you about their life. Storytelling is a safe place for a patient to share information and express feelings, as stereotypes and assumptions can be shattered, leading the way to patient affirmation by the nurse (Heliker). Using the analogy of reading a text, Kahn and Steeves (1986) compared the text to the patient’s experience of suffering, the reader is the nurse, and the context is the interpretation of the story by the nurse, which reflects physical, psychological and socicultural features of the patient’s story. The parts of this analogy are inseparable and are meaningless, if separated Kahn & Steeves, 1986). Ferrell and Coyle (2008) made a poignant example of the importance of stories in relation to an infant dying and the emptiness and void of meaning that was felt by loved ones and health care providers, because the child had no stories to tell. Without stories there is little past, no dreams of future, very little context of life itself.

To synthesize meaning in a story being told by a patient requires acute listening skills or what is referred to as “narrative competence” (Charon, 2001, p. 1897). This is the competence to actively listen, interpret, and respond appropriately to what the patient is telling, all the

while incorporating what is not being said, moments of silence, language used, gestures, and physical findings. It is the listener's responsibility to synthesize contradictions of words and meaning, discover hidden values, and to find some pattern to the randomness of illness (Bernick, 2004; Charon; Heliker, 1999). Charon referred to this type of care as authentic engagement in which empathetic and effective therapeutic relationships can be achieved. Byock (2002) stated "Life review and the soliciting, telling, and receiving of persons' stories is another tangible example of components of care that extend beyond attending to basic biologic and emotional needs" (p. 285).

Watson's (1997) perspective of transpersonal caring embodies the qualities of "authenticity of being and becoming, an ability to be present, to be reflective, to attend to mutuality of being and centering one's consciousness and intentionality toward caring, healing, wholeness and health" (p.51). Narrative competence, authentic engagement and extending care beyond the basics are illustrative of the advance practice nurse who seeks to understand the world of the patient. In a role as educator, leader, advocate and using reflective decision making, the advance practice nurse is able to synthesize components of the patient's situation and the meaning that suffering and illness have for any particular patient. New meanings emerge to a caring practice whose focus is central to the values and needs of the patient and their experience of illness.

Listening to a patient tell a story is an example of extending care beyond the basic needs of the patient. Listening also implies presence, which is identified in the literature as characteristic of caring nurses and offers great relief to patients and families who suffer in illness (Ferrell & Coyle, 2008). Benner (1982) referred to the practice of an expert nurse coping with illness through learned ways of being. Cassell (1999) used the analogy of an open door to the inside of you, the clinician, so that the patient may enter and experience you for who you are and not

what you do, leading to a trusting relationship. Ways of being present may be learned through experience as nurses learn to trust their intuition and reflect upon the experience of working with patients who suffer. Ferrel and Coyle (2008) considered the art of presence in midst of suffering a basic and critical component of nursing.

It is difficult to minimize one's doing when we measure our productivity by how much we do in a demanding environment. Voice and touch are essential to overcoming the effects of anesthesia in a recovery room and premature infants, when old enough, are comforted through sensory enhancement of touch (Benner, 2004). Benner referred to touch and solace as endangered arts of nursing which serve to fortify and refresh those who suffer.

Presence also implies attitude in the way we offer care to patients who suffer. Benner (2004) shared the observation of a nurse working late at night to change an intravenous solution in an infusion pump while the patient and his wife engaged in a quiet dialogue. The nurse entered the room, looked at the couple, quietly acknowledged their presence, and proceeded with the task at hand. The nurse honored their privacy as if this were their own room. Her attitude was one of respect, honor, and humility. Knowledge of one's attitude requires self-reflection on assumptions one might have regarding a patient (Chochinov, 2008). One's assumptions about the patient may not be accurate, which could result in an ineffective and meaningless plan of care for the patient and prove to exacerbate patient suffering. Self-reflection can aid in the professional development of a nurse and enhance advanced nursing skills required in working with patients who suffer. Chochinov (2008) suggested the following questions be asked to examine one's attitudes:

How would I be feeling in this patient's situation? What is leading me to draw those conclusions? Have I checked whether my assumptions are accurate? Am I aware how my attitude towards the patient may be affecting him or her? Could my attitude toward the patient be based on something to do with my own experiences, anxieties or fears? Does my own attitude towards being a healthcare provider enable or disable me to establish open and empathic professional relationship with my patients? (p. 18)

In summary, the literature review illustrated the effect suffering has on the four aspects of being – physical, psychological/emotional, sociocultural, and spiritual. There were several sources that focused entirely on the spiritual nature of suffering. But often, those that referred to a multidimensional view of suffering, neglected to mention spiritual suffering.

It is apparent from the literature review that there remains a gap in the cultural component of suffering, as only three sources acknowledged the importance of cultural norms and rituals during illness and death. Also noted was the lack of literature on the importance of alleviating versus eliminating suffering. Even though there is research on how patient suffering may effect a nurse witnessing the suffering, there is no research on nurses' perception of patient suffering.

Connecting caring to suffering proved to be essential in tying together all aspects of this study. The purpose of this study is to explore nurses' perception of patient suffering, providing greater insight into a caring and healing nursing practice. It aims to raise the level of awareness of patient suffering for nurses, and thereby serve as a basis for reflecting on the impact of their nursing care on the health of the individual and patient outcomes. It also aims to advance the knowledge base of nursing science by enhancing the advance nursing skills of connecting the mind, body, and spirit and provide new meaning to clinical care. Watson's theory of transpersonal caring informed this study by emphasizing the importance of authenticity of being, the act of being present, and the use of reflection and active listening in serving those who suffer. The value to the study is the accurate representation of the data illustrating how nurses perceive patient suffering.

The pattern of storytelling, which began in the literature review and continued into the data analysis and discussion, gave the researcher pause for thought. Many of the sources in the literature review used patient stories to illustrate the ideas being discussed. Likewise, the nurses being interviewed for this project used stories about their patients to illustrate their

perception of patient suffering, and the nurses' stories were used in the data analysis of the narratives that were told. The singular importance of stories used in this project highlights the unique quality and individual nature of suffering and the deep, personal meaning given by the patient to the suffering being experienced. Storytelling, which was initially revealed in the literature review, emerges from the study as a significant form of communication, intervention, and self-reflection, holding value and meaning for both patients and nurses.

CHAPTER IV

METHODOLOGY

The purpose of this study is to explore nurses' perception of patient suffering in order to provide greater insight into a caring and healing nursing practice. By raising the nurses' level of awareness of patient suffering, nurses may reflect on the impact of their care on the health of the individual and patient outcomes. The use of an unstructured interview allows the participant to think freely and express oneself without constraint. Qualitative descriptive methodology best preserves the integrity of how nurses come to perceive patient suffering and was used to allow the data to be truly representative of what was said (Sandelowski, 2000). Phenomenological methodology would provide a basis for synthesizing the meaning and the lived experience of nurses working with suffering patients (Morse & Johnson, 1991). Ethnography would interpret the narrative, providing generalizations about nurse's understanding of patient suffering (Morse & Johnson). Grounded theory would what to know what is happening here and use control in choosing participants to confirm or challenge hypotheses that emerge in the narratives (Morse & Johnson). Qualitative descriptive studies have the sole intent of summarizing in ordinary language an accurate representation of data collected, proving useful to the intended audience (Sandelowski). Descriptive validity is established by the fact that most people would agree that what is being described is indeed an accurate account of what was said and language simply represents a means of communication and is not meant for interpretation (Sandelowski). Descriptive studies can in turn provide the basis for other types of qualitative research such as phenomenological, grounded theory, or ethnographic (Sandelowski).

Just as a relationship develops between a nurse and patient in which expectations, fears, and apprehensions are shared, by transposing this idea of transpersonal relationship (Watson, 1988) to the researcher and participant, the individual perception of suffering is respected and remains true to the word. In addition, this research method models the definition of suffering as an individual experience, unique to the individual and deeply personal (Daneault et al., 2004; Ferrell & Coyle, 2008; Gadow, 1991, Kahn & Steeves, 1986; Lindholm & Eriksson, 1993). In the clinical context the nurse is challenged to understand the meaning of the suffering experience for the patient. In the research context, the challenge for the researcher is to encourage the nurse to articulate perceptions of patient suffering. At the same time the patient is having a deeply personal and individualized experience, the perception of the patient suffering may be an individualized experience for the nurse. If one is confident in the Theory of Human Caring and the Theory of Cariatative Caring, it may be difficult to separate the two. Therefore, the need for direct and accurate reporting is necessary.

Design and Setting

Given the complex nature of suffering, the use of qualitative descriptive study was well suited to arrive at an accurate description of how individual nurses perceive patient suffering. A digital audio recorder was used to collect data from the participants via unstructured interviews from June, 2008 to September, 2008. The interviews lasted from 45 to 90 minutes with an average time of 50 minutes. Face to face interviews provided an opportunity to get to know the participants and contributed information via verbal and non-verbal communication. Interviews were conducted between 8 a.m. and 9 p.m. at various locations convenient in time and location for the participant. Network sampling was used to garner participants at places of employment, professional meetings, school, and word-of-mouth referrals (Lobiondo-Wood & Haber, 2006). An email was sent to prospective participants introducing the researcher and

project and explaining informed consent (Appendix A). The consent form also informed participants of the option to review the final transcription for accuracy. Twenty-two emails were sent, resulting in 8 nurses indicating an interest in joining the study. Time and location of the interviews were arranged at the participant's convenience.

Procedure for Data Collection

Prior to the interview process, the researcher wrote down personal thoughts and perceptions of patient suffering. This exercise in bracketing was to provide a frame of reference for the researcher during the process of interviewing and analyzing data. Bracketing, as explained by LoBiondo-Wood and Haber (2006) is a way to single out personal biases, so that the researcher is able to focus on significant issues raised by the participants in the study, rather than leading the participants in a direction. Putting aside these thoughts helped to prevent participants from being lead and minimized judging of person or information, adding to accuracy of content analysis. The taped interview began with informal dialogue providing a relaxed environment and time for the participants and interviewer to come to know one another. The nurses were thanked for participating, the purpose and process of the interview was explained; questions answered; confidentiality of information was once again assured; and the informed consent was reviewed and signed. The participants were asked if they had a current RN license, even though it had been stated as the only requirement in the initial email.

The participants were asked how long they had practiced nursing and in what areas of nursing they had experience. An open ended question - How would you describe patient suffering? - introduced the topic, followed by general questions, which were used to prompt exploration of information already verbalized. Prompting questions included: How do you know when a patient is suffering? Tell me about your experiences of caring for patients who suffer. Is there any one experience that is most meaningful to you? How did you handle it? Is

there anything you would have done differently? In five of the eight interviews, one or more guided questions were used and, in all the interviews, prompting comments or questions were used to maintain a train of thought, to explore an experience in greater depth, to reframe a thought, or to acknowledge what was said. There was no attempt to guide the participant in a certain direction other than to keep them focused on patient suffering. Silence was an important component of the interview process, which allowed for personal space of the participant and for collection of thought on the part of the participant and interviewer. This also contributed to the pacing of the interview process, which is important in maintaining a relaxed environment in which thoughts are allowed to flow freely. Several participants ended the narrative on their own, in which case, I summarized what was said. This summary many times prompted more narrative from the participant. In other instances, as the narrative was slowing down, I indicated that time for closure was nearing and asked if they would like to summarize their thoughts. The data was transcribed verbatim using Digital Voice Editor Version 3.1, which allowed for flexibility in volume and speed of speech, searching for text, and stopping and starting. Following the transcription process, an email was sent to each participant thanking them once again for their participation and assuring that the content of their narrative would serve to enrich a body of knowledge that would raise the level of awareness and help all nurses to better understand patient suffering.

Data Analysis

Content analysis was used to analyze the data and commenced as soon as the interview ended. Through a reflective process after the interview, broad observations of the participant's non verbal behavior and demeanor, tone of voice, language used, emphasis and omission of themes presented in the literature were written down. Audio recordings were transcribed by the researcher into the computer within two days. Once transcribed, the data was printed and

stored in a locked drawer in the researcher's office desk. Only one participant chose to review the transcription for accuracy and no comments were forthcoming from the participant. After writing the study, the audio recorder and transcribed material were placed in a locked safe at the residence of the researcher, where they will remain for three years. The purpose of which is to provide an audit trail for use in confirming the methodology and outcome of the study and to fulfill requirements of the Institution Review Board for the Protection of Human Subjects at the University of New Hampshire.

In the next step, each transcribed interview was reviewed by simultaneously listening to the audiotape and reading the transcription to check for accuracy. Content analysis commenced and, after the second reading, broad themes were noted. After several readings, reoccurring themes emerged and were organized from most prevalent to least prevalent, which facilitated a plan for documenting the findings. Reflective notes were consulted to provide a comprehensive view of the data collected. Eight themes emerged from the narratives, each of which was cited by at least three participants and some themes by all eight participants. The themes include the general nature of suffering; the four aspects of being impacted by suffering – physical, psychological/emotional, sociocultural, and spiritual; the inability to relieve suffering; the importance of presence; and storytelling.

Rigour

Rigour is the means by which we achieve integrity and competence in qualitative research and is measured by goodness as a way of determining trustworthiness and authenticity (Tobin & Begley, 2004). Arminio and Hultgren (2002) listed six elements which establish goodness: theoretical foundation, grounding through methodology, explicit data collection method and management, established relationship between participants and researcher, established new

meaning through data interpretation and management, and implications of the research in professional practice.

Rigor is reflected in the development of this study through the following points. A theoretical foundation in the Theory of Human Caring was introduced in the literature review and followed up in the discussion of the findings. An audit trail was established in the clear documentation of the research method employed in this study, the preservation of data on audio recording for three years in a locked safe, and a bound copy of the study at the University of New Hampshire Library available for examination by the public. The use of qualitative descriptive methodology, with no attempt to synthesize meaning or interpret the narrative, helped to ensure accuracy and validity of the spoken word. Self-reflection prior to beginning the interview process and the bracketing of personal biases provided for objective representation of the narratives. Tobin and Begley (2004) stated “tactical authenticity is established through empowering others” (p.392). The informed consent letter included an option for the participants in the study to review the transcription of their narratives for accuracy (Appendix B), however only one participant exercised this option and no comments were received. Implications for the research assembled in this study were applied to nursing practice, nursing education, and future nursing research.

Limitations of the Study

Limitations of the study can be seen in the small sampling of participants. However, with a descriptive study, a small sample can provide significant data for future work. This study provides a foundation for answering questions, which emerged from the study, as evidence in the section on implications for future research. Also lack of experience in conducting interviews for research purpose and analysis of data should be considered a limitation when reading this study.

CHAPTER V

DATA ANALYSIS

Data was analyzed using content analysis. Marshall and Rossman (1989) explained that one of the purposes of content analysis is to produce descriptive information. A content analysis was used to analyze the data from unstructured interview with the objective of discovering shared and differing impressions of patient suffering as experienced by the eight nurses participating in the study. There was no attempt to give meaning, interpret, or prove a hypothesis in the analysis of the data. The strongest feature of content analysis is that it can be conducted with objectivity, such that the researcher is an observer, who does not react to the information given and is not set to prove a hypothesis (Marshall & Rossman, 1989).

Once the data was transcribed, the transcription was reviewed by simultaneously listening to the audiotape and reading the transcription to check for accuracy. Significant passages and information that the participant emphasized or repeated in the narrative were highlighted. After the second reading, broad themes were noted within the highlighted data. After several readings, patterns were identified and specific themes and sub-themes emerged. Using a method referred to by Marshall and Rossman (1989) as “absolute frequencies...the most common method of summarizing content-analytic data” (p.100), themes and subthemes were organized from most prevalent to least prevalent.

A descriptive narrative was used to explore nurses’ perception of patient suffering. An unstructured interview provided the foundation for the narrative given by the participant and allowed for the participant to think freely and express oneself without constraint of an agenda. An open ended question was used to introduce the topic, which may have been followed by general questions used to prompt exploration of information already verbalized. Realizing that

it would be impractical for entire interviews to be cited, the choosing of portions of narrative to be used is inherent in the process of analysis (Sandelowski, 2000). To disagree with Marshall and Rossman, this choice represents a subjective thought process. To be true as possible to the descriptive process in the content analysis, a self reflective exercise of the researcher's own perception of suffering was written. Bracketing these perceptions helped to facilitate an accurate and objective as possible rendering of narrative chosen to be cited (Lobiondo-Wood & Haber, 2006).

The research participants for this study were eight registered nurses with a range of nursing experience from one and one half years to 34 years with an average of 17.75 years experience. Areas of expertise represented by the eight nurses were obstetrics-gynecology, medical-surgical, hospice, intensive care unit, cardiology, and community health. A variety of employment locations included large urban hospitals, small community hospitals, rehabilitation centers, and a hospice house.

Because of the small number of research participants, it seemed appropriate to introduce them on an individual basis. To protect the privacy of those participating, anonymous first names have been assigned to each participant. A brief introduction will help to place their narratives within a context of experience, both personal and professional. The context in which a patient suffers, the physical, psychological, sociocultural and spiritual environment, is an important consideration for nurses working to alleviate suffering (Kahn & Steeves, 1986). Likewise, the context from which a narrative is spoken gives strength and credibility to the experience the nurse is reflecting upon, and is important for the reader to consider when the data is analyzed and discussed.

Amy is a nurse with 25 years experience in medical-surgical, pediatrics, and family services. She has work with families from different cultures in home care. Coming from a

strong religious family, she initially studied theology and then decided to pursue a nursing career. She revealed many personal experiences with major surgery and addiction within her family, that have effected her practice as a nurse. The interview was conducted on the deck of her home overlooking a landscaped yard with flower and vegetable gardens. She appeared relaxed throughout the interview and truly engaged in the subject matter.

Betty has one and one half years experience working at a rehabilitation center. After many years working in business, she decided to study nursing. With a masters' degree in nursing, she is currently pursuing a nurse practitioner's degree. The interview was to be held at a picnic area, but due to a downpour of rain, we ended up in the researcher's car. The pounding of rain on the hood and roof provided an interesting acoustical effect, which the participant thought was wonderful. A sense of humor and optimism is evident as she recalls her work with those seeking to return to a normal way of living following surgery and illness. She admitted that she was much more interested in the science of nursing than the art of nursing, but thought the topic of suffering may spark a thought process.

Claire began her nursing career 25 years ago on a medical-surgical floor. As a young nurse she wanted to take care of those who needed her. Experience in mental health and working closely with a spiritual care director at a small community hospital led to 15 years of work in hospice where she currently works today. She hopes never to lose the sensitivity and compassion she felt early on in her career as she learned to struggle with drawing boundaries between herself and her patients. Claire spoke with passion and conviction as she recounted her own personal growth in spirituality in working with those who suffer. The setting for the interview was an early morning walk along the ocean, which served to enhance the spiritual narrative of this nurse.

Demy worked three years on a medical-surgical floor before focusing on labor and delivery at a large urban hospital, where she has worked for 23 years. She is now a nurse educator working with new employees in orientation, teaching what she learned as a bedside nurse. As a graduate student pursuing her master's in nursing, she was eager to participate in this research project. She stated that psychological pain is difficult for her to deal with and she is more comfortable treating physical pain that can be observed. Use to the activity of an urban setting, the participant was quite comfortable being interviewed at a fast food restaurant.

Elaine calls upon 28 years of nursing experience in a variety of domains in her role as an educator and staff nurse. As a nurse practitioner, she states that she is able to see people and suffering from a holistic and global perspective. She continues her knowledge pursuit through professional organizations and attending programs such as those offered through End-of-Life Nursing Education Consortium (ELNEC). The interview was held at an outdoor patio in the late afternoon at Elaine's place of employment and provided peace and quiet as she reflected upon her past experiences with suffering.

Florence is a vivacious novice nurse of one and one half years currently working on a medical-surgical floor. Even though she acknowledges physical and emotional suffering, she recognizes a lack of knowledge base in end-of-life care. A background in psychology helps her look beyond the observable to other possibilities in suffering. Florence did not reveal any personal stories of suffering. The interview was held at an outdoor café and was interrupted briefly with a short conversation with an acquaintance of Florence's. A notation was made as to the thought being expressed prior to the interruption and we proceed for only an additional few minutes.

Gwen has spent 22 years of nursing in cardiology, including medical surgical, catheterization laboratory, and cardiac rehabilitation. She expresses great stress in not having

enough time to address issues of suffering with her patients. She appears resigned to the fact that as a nurse she cannot do it all. The interview was held in a quiet corner of the lobby of her place of employment during her lunch break.

Hallie is a soft spoken woman with a passion for her work as a hospice nurse coordinating end-of-life care for hospice patients in hospitals. Her experience in alternative healing methods has served to enhance her healing and compassionate nature as a nurse of 5 years and enables her to understand the whole picture of patient suffering. The interview was held at the end of Hallie's work day at an outdoor café. She related a very taxing day, but was relaxed in thought and demeanor and seemed to enjoy just being able to think and speak freely.

Emerging Themes

Figure 2 is a visual representation of the themes, which emerged in the data analysis and were the basis of discussion.

Theme 1: General Nature of Suffering

Theme 2: Aspects of Being

Suffering and Physical Being

Suffering and Psychological/Emotional Being

Suffering and Sociocultural Being

Suffering and Spiritual Being

Theme 3: Inability to Relieve Suffering

Theme 4: Presence

Theme 5: Storytelling

Figure 2. Emerging Themes from Data Analysis

Theme 1: General Nature of Suffering. The question, how do you describe patient suffering, was used to initiate thoughts for the narrative and prompted replies, which expressed

general views about suffering. The question was not always answered right away, but was revealed in the narrative by the participant or was revisited towards the end of the interview when the researcher was summarizing the narrative. The responses were as varied as the individuals and, many times, provided a framework for more elaborate thoughts. “Addressing suffering is the crux of nursing...If you can’t address your own suffering, how can you address the suffering in others” (Amy). “Recognizing suffering, the most important thing is being, not doing” (Claire). Most of the nurses acknowledge that suffering goes beyond physical pain. “If they are not physically suffering, I look at challenges they are up against.” (Betty). “Suffering is a long term event...A patient can have short episodes of acute pain, but suffering is always there in the background waiting to get more powerful than your brain can take care of” (Demy). “Suffering used to be thought of as just physical – the pain of suffering. We’ve come to realize that suffering is much richer and deeper – many layers”(Elaine). “Pain is suffering, but people do not always suffer because of pain”(Florence). “Physical pain is suffering and then there is depression, which causes great suffering for people” (Gwen). “Suffering to me is whatever discomfort the patient feels – emotional, physical, spiritual...People struggle with suffering like they do with death and dying” (Hallie).

Theme 2: Aspects of Being. Amy, Claire, and Hallie implied the presence of physical suffering is integral to emotional and spiritual suffering, but their perceptions did not speak directly to physical suffering. They moved beyond the presence of pain in their assessment and considered the interaction of all aspects of being.

Other nurses used physical pain as an initial indicator of suffering and then looked at other implications. Betty related her nursing practice to the physiological process of pain and how it effects the sociocultural aspect of being when she stated, “I see physical suffering in the morphine that constipates my patients and because of the pain, they do not want visitors to

come... the shortness of breath for a man dying of pulmonary fibrosis and how he extends himself to the very limit of his abilities because he does not want to give up being independent.” level to expect from their disease or surgery.” Elaine questioned the shortcoming of assessment that does not go beyond physical pain: “If we are in tune with and listening to emotional and spiritual pieces, it can ease physical pain, and sometimes we do it backwards. When the pain management is maxed and you’ve done the best you can, people leave it at that and don’t go any further.”

Demy, Florence and Gwen discussed assessment of physical pain. Demy explained, “Not all pain is equal. People do not perceive pain in the same way. That’s why pain management can be so difficult. We have learned a lot over the years, but even the pain scale is difficult for some people to use, because they don’t know what pain level to expect from their disease or surgery.” Florence stated “Physical pain is seen in high blood pressure, high respirations, screaming, crying, grimacing.” Gwen responded “Physical pain is the most common and most obvious. It is difficult to find out if a person is in pain if they don’t show any signs or symptoms. Many times they are stoic, think they deserve it. It can be a male thing that you are weak if you show you are in pain.”

Impact of suffering on the psychological being included two accounts of fear, working with patient addiction, and depression. In her practice, Amy greeted all of her patients with the same assumption and commented, “I use the same premise that everyone that comes through the door in same day surgery is suffering - terrible fear of some degree of fear of the unknown. Even if you’ve had the surgery six times, each time can be different.” Hallie recalled conversations with patients who are not sleeping at night and how it led to other problems. She commented, “One of the most common conversations I have is about fear, which can lead to insomnia, pain, and anxiousness. I listen and let them talk more and they say they are afraid

that if they sleep they will never wake up. They tell me this, not their family.” Later on in her narration, Amy reflected upon her work with people with addiction: “The people I feel least able to relieve suffering are alcoholics and drug addicts. Very challenging for me. I’ve gone to Al-anon because of my husband... Being able to accept my limitations to relieve their suffering is hard.” Demy acknowledged that drug seekers are in pain, but early in her career at a large urban hospital she had little empathy for them.

One day I spoke with my mother, a nurse, who explained, ‘your patient is in pain, someplace she is in pain and isn’t it your job to help her deal with the pain and then help her to find help for her pain. This put a new thought process in my brain about psychological pain and how there can truly be a lot of pain. What I now try to do is determine what the problem is, how can I help them, do they want to change, do they know they have a problem. If they do want to change, then let’s get them help to change.

Claire described the signs and symptoms of suffering, many of which contain an emotional component. She explains, “Very often they are withdrawn, no eye contact, they’ll say ‘what’s the use’ or be very angry and say ‘get the hell out of here’. They are listless and hopeless, lonely and very sad. Don’t want anything to do with you or anyone else.” Florence understood patient suffering through her experiences with suffering when she stated, “You can see emotional pain as a nurse, but you don’t know what it is like unless you are in their position. If you’ve had the experience yourself, you can empathize with the person. Can’t ever really know unless you’ve been in the situation.”

Gwen expressed considerable thought about depression, but limits her assessment to thinking about emotional suffering and does not pursue what it means for the patient in an effort to alleviate the suffering.

I think people who are depressed must suffer. Depression can be so debilitating. It is easy to think that because someone is quiet that they are depressed. But it’s more a look about them that makes me question whether they might be depressed. The slumped posture, the far off look in their eyes, the one word answers... I think when they are already depressed, to be ill and not feel well or to go through the anxiety of surgery, has got to make the situation worse. I think they are probably suffering at that point, but I never really thought much beyond that.

Suffering within the sociocultural being was highlighted in the communal nature of suffering. Even though families were mentioned, it may be difficult to for some to incorporate the importance of other people into the personal world of the suffering patient. Amy, as a home care nurse working for family services, gave the following examples, “ Cultural suffering is interesting. The Asias don’t express any pain. The Spanish and Indians are very dramatic”.

Elaine spoke of the use of nursing intuition in assessing suffering and how, by watching the scene unfold between patient and family, a nurse can gather a more comprehensive picture of the patient’s world.

I think there is a piece of the assessment that goes unnamed and that is nursing intuition. I can feel that intuitively. I can feel it in my chest and stomach – when I look at them and and touch them. That’s part of it. You watch family and caregivers and you watch the patient respond to them in a certain way and that gives you clues that this patient is suffering – facial grimacing, moaning, eat little or too much, very individualized. All those things together help the nurse assess suffering.

Likewise, Florence shared a story of a patient with exacerbation of chronic obstructive pulmonary disease (COPD) and the family dynamics that resulted from his suffering. The lack of involvement by the family within the realm of the patient’s suffering was highlighted.

Every time he moved, he was short of breath. He was suffering because of end stage COPD and he knew that, but his family around him was really suffering – crying and more upset by the whole experience than the patient. All he wanted was his breakfast. So while all this was going on, he asks for his breakfast, ‘I’m starved and just want to eat’. He wanted to stay strong for his family.

The nurses that spoke of spiritual suffering interwove spirituality throughout their entire narrative, so that it serves as a paradigm for reflection upon their entire nursing practice. Amy summarized, “In my experience, when you can get to the spiritual level with patient’s suffering, you get to the right track – you’ve gone to the right place...when patients can get to their own spirituality, facilitating that with patients is very special. I did not have that when I

had surgery and was suffering.” Claire admitted that she could not talk about hospice without talking about faith.

There is a mystery to suffering. It draws us into the spiritual realm. Sometimes the people have faith, sometimes they have no faith. They are the challenges because they have even lost the ability to love themselves and they need to be loved. I do not know how those facing the end of life get through it without some form of spiritual grounding. It’s very difficult. Some people are religious, but do not have a deep spiritual understanding of where they are going and who they are. But a deep spiritual person, not necessarily related to the church, seems to be able to connect to something beyond.

Elaine related a personal story of a loved one, who had lost the will to live and no one appeared able nor was inclined to address the suffering.

We are still tiptoeing around the real issues of the human spirit, death, and dying.... She could not live in her apartment anymore with her dementia and host of other comorbidities. So we moved her to a long term care facility and I’ve watched her decline. They are so focused on giving her medications to speed up her appetite. No one wants to talk to her about her suffering. She just wants to die, she hates it there...so hard to watch. The social worker calls and says she is not participating in any activities, she doesn’t act happy, we offer her things and she doesn’t want to do anything, she’s not eating. Just calling to tell you. Yeah, she just wants to die. This is not her idea of living a good life, she is fiercely independent. I think people are afraid to talk to her about suffering.

As a hospice nurse, Hallie was most comfortable talking to patients about spiritual suffering, because she admits she is comfortable with her own spirituality.

The spiritual suffering people have in our everyday life is because we can’t discuss things. When we can’t forgive someone, we suffer. People are tougher on themselves than anyone else could be, so they have a difficult time with forgiveness. I try to help people be forgiving of themselves, because that can cause a lot of suffering. I see it in restlessness, fear of going to sleep, worry about relationships, things they did and did not do. They are stuck between two places. The body is ready to go and they just cannot leave it.

Theme 3: Inability to Relieve Suffering. The inability to relieve suffering emerges in many of the narratives. Amy explained that determining what is comfortable for someone else is difficult, so she goes by what type of care she would want at any given moment. She explained, “Just because it is your feeling, doesn’t make it their feeling. I don’t want to judge suffering. I don’t know or understand it all. The only thing I can understand is how I wanted to be treated when I was that frightened having to have surgery.” Later on in her narrative, Amy

reflected, "Nursing is fraught with regret, knowing that I did not relieve pain as effectively as I had hoped. Just realizing my own limitations as a human is what I have a hard time with.

There are times when you have to send people on their way to work on their own destiny."

Florence related working with suffering from a personal perspective as well, " And even though you can see emotional pain as a nurse, you don't know what it is like unless you are in their position. If you've had the experience yourself, you can empathize with the person. You can't ever really know unless you've been in the situation." When asked how do you as a nurse help someone who is suffering, Betty responded, "I don't know that I am able to help, honestly. I ask him what he wants, instead of what I think I should do. I do things when he wants them and how he wants them, so that he is able to maintain some kind of control." To the same question, Gwen expressed resignation to the fact that she just cannot do everything.

I think of the patients I care for who were suffering obviously – displayed signs and symptoms of really hurting inside. Sure, I would do my best to make things better. It's the ones you don't know about. You might suspect or have a gut feeling, but do you have the time to act on it when there are call bells ringing, doctors calling you back, someone passes the doorway and you've been looking for them for hours – so many distractions. And that fleeting thought you had about your patient who might need comforting, gets so lost...I think with nursing, you just have to accept that you can't do it all.

Theme 4: Presence. The nurses who referred to spirituality in their narratives make a connection between the spiritual aspect of being and the presence or the ability to simply be and not feel the need to do. Amy used such words as "synchronicity" and "bonding", that once attained in the relationship with the patient, enable her to dig deeper into the patient's world of suffering. She further explained, "Familiarity is an excellent tool to handle suffering. We talk, but words are an adjunct, not really the key. Behavior is most important. Eye contact and listening are key to being with the patient." Hallie, on the other hand, viewed the use of words as integral to her work as a hospice nurse, so she listens and responds. She discussed the process, "When I go in and have these conversations, it is not just me. The words just come. I

don't sit at home and come up with these words. They just come and I am guided. I feel like a tool. I hear it, I allow it, I don't question it. I just continue to try and listen.”

Hallie illustrated the art of presence and in simply being and not doing or fixing with the following story. As she explained, the use of the word simple does not mean that it is easy.

Early on in my career I worked with a psychiatric nurse. She would sit in silence for long periods at the bedside of a patient who was suffering. She would sit for the longest time not saying a word. Sometimes the patient would talk and sometimes not. I would walk out into the hallway after our visit was over and say to her, ‘How can you sit there for so long and not say anything. The silence is almost unbearable for me?’ She explained that silence gives the patient time to think, to ponder. You don't say anything and they tell you everything. It's amazing how effectively you let people share their feelings. That you sit comfortably in silence, helps them trust you.

The use of silence and companionship was an important part in Claire's work as a hospice nurse as well. Claire reaffirmed her strong feelings in the following narrative.

Over the years I have learned there is not a lot we can do when someone is really suffering. Can't always take away the pain, but can walk with them and in so doing we experience the helplessness that those close feel when a loved one is dying and there is nothing they can do to stop the process. I do think we can be a tremendous help to someone suffering just by being present. To communicate is through the language of silence. There are no words when someone is really riddled with intense suffering physical pain, emotional, or spiritual suffering. Difficult to stand and just be present, but sometimes that is what they need.

Having worked as a nurse in many different settings, Elaine felt strongly that suffering takes different forms and could be addressed in any venue by the way you treat people.

It's not even about nursing, but how you treat people. The use of eye contact, the phone call the day after even though it is not needed. Not even about nursing, but how you want to treat people. Even with nursing today being so busy on the floor, if it is in you, part of your belief system, if it's been cultivated, you'll find a way to do that. There is a way of being with people when you know they are suffering.

Theme 5: Storytelling. The nurses participating in this study were earnest about sharing stories, not only of patients with whom they worked to alleviate suffering, but also to articulate their perception of suffering. The use of storytelling contextualized the nurses' experience in the perception of patient suffering. Many of the stories were early in their nursing careers and

provided a vivid memory of the impact this experience had on them as novice nurses or how it changed their nursing philosophy of care.

Amy felt strongly about giving her patients hope and it was revealed in the following story.

Late at night I prayed and sang with a man who was a musician, wife died, a diabetic, neglected and grieving. He had put away his instruments after his wife died, because they used to play together. I washed him and shaved him. Years later, he was my patient in a nursing home and when I told him who I was, we sobbed and he said I was an angel that night. Talk about synchronicity. I was able to relieve his suffering because of the bond between us – not me per se. Just being the vehicle for that to occur.

Claire shared several vignettes that highlighted things patients had taught her in working with those who suffer and have served to change her nursing practice.

A young girl, early forties, with ovarian cancer, always trying to tell her family – just listen to me. Family was always trying to do something for her. Now days when we are all in there trying to fix the problem, make things better, and do whatever, and all we need to do sometimes is just listen. Another woman, a school teacher, had a tremendous need to teach. Everytime I went to visit with her at home, I'd sit at her kitchen table and she'd say, 'Now you are going to have another lesson today.' That was her way of coping. She would do research on diseases and the latest treatment, and I would have to sit and listen to her a little bit before I even took her blood pressure. I will never forget this little old lady with lung cancer. She would want me to sit in her kitchen, have a cigarette, and pray Hail Mary's with her. We did this for about four weeks. One day she says she wants to give me something. She handed me a little envelope of miraculous medals. They have been a theme in my life ever since. Taught me the need for letting go and for family members to have closure.

Demy has struggled with a past experiences in which she was unable to recognize the patient's problem and, therefore, the patient suffering was not addressed.

I had a patient who was vomiting. The physician ordered medication to be given intramuscularly or rectally. I don't like injections for myself. I went to the patient and said you can have this by a shot or I can give it rectally. She went off, 'put it in my bum, put it in my bum, put it in my bum'! She went on and on. I went, no, no, no, I can give it to you in a shot. And it was not till years later that we were learning about adult behavior of women and men who had been sexually abused early in life and had been penetrated rectally. They don't want anything rectally. I thought of that woman and thought, oh my God, I didn't do anything for her. I didn't recognize the problem. And that really hurts when you don't recognize the problem or you miss what they said to you and on the way home you go, oh my God, that is what they were trying to say to me. It's these people years later are still like my ghost. I wonder how they are doing.

Elaine recalled an experience early in her career when nurses could sit with their patients at bedside and comfort them.

She was dying of ovarian cancer and I came very close to her for a period of two and a half weeks. I came to understand what suffering meant to her. I witnessed the great suffering she had because of letting go of her family, abandoning them, trying to figure out whether she believed in God, her body image changed so drastically, her whole womanhood became a huge issue for her. And that has stayed with me all these years... As she was dying she loved to read and being an avid reader, I sat and read to her. It helped her suffering. You talk about Watson's active presencing. To sit and be and touch and connect and eye contact and have that intuitively energy connection is pretty profound.

The following story told by Hallie reaffirms her belief in the power of words to help people through their journey of living to the end-of-life.

I had been a hospice nurse for two years when I began working with a lovely woman with advanced stages of chronic pulmonary obstructive disease, took her oxygen off to smoke. She was telling me she wanted to die. Her husband had died. She was Catholic, believed in heaven, and wanted to join her husband. She was angry at God cause he would not take her. She was sleeping, but not eating. Could not figure what was keeping her here. One day she was afraid to take morphine. We talked. I said, 'You are angry at God cause you want to die and he won't take you. But are you actually worried about something?' I assured her we would keep her comfortable. I said, 'Did you have a good life?' She said, 'No, I did not. I took care of my parents and my husband. But my parents did not treat me well.' I said, 'Are you afraid to see them in heaven?' She said, 'Yes, I am.' I said, 'Do you think God would let you go to heaven and let people be unkind to you there?' She said, 'No.' I said, 'When you are ready to go and can decide that, pack your bag with good memories and leave the bad behind. 'Okay', she said, 'I like that.' Two nights later she said to her neighbor, 'Get my suitcase and pack my good memories.' 'Mary,' the neighbor said, 'where do you think you are going?' Mary died later that night, very peacefully. She taught me that if you just talk it through, sometimes people are afraid with what is next. Talk it through, pose questions to let them think about things, from their perspective how do you think about things. In your life I think the spirituality is inside and that's how we find our comfort and how we get through life.

The retelling of these stories of experiencing patient suffering by nurses who cared for them was a testimony to the individual patients and showed great respect and honor for their struggle to live and courage to die. For the nurses who told these stories, the process of self-reflection may have enriched their nursing practice and enhanced the care, compassion, and commitment to other human beings.

CHAPTER VI

DISCUSSION

The themes which emerged from data analysis are reflected and supported by much of the literature reviewed for this study including, the impact of suffering on the four aspects of being – physical, psychological, sociocultural, spiritual and their interaction within the whole person, the inability to relieve suffering, presencing by the nurse, and storytelling. Just as Cassel (1982), a seminal author on the topic of suffering, called upon medicine to make an obligation to the relief of suffering, Lindholm and Eriksson (1993) stated in reference to nursing, “The alleviation of suffering has always been the cornerstone of caring (p.1354). There is little doubt that the nurses interviewed for this study care for their patients. But either through experience, knowledge, an acquired comfort in confronting suffering, or other unknown factors, some of the nurses appear more prepared to address suffering to the full extent it impacts the personhood of the patient than others. The wide range of nursing experience and the variety in expertise and local of practice of the nurses interviewed, offers a broad context from which we may come to understand how nurses perceive patient suffering. This understanding aims to provide greater insight into a caring and healing nursing practice.

Ferrell and Coyle (2008) suggested levels of suffering in their attempt to define the nature of suffering. I have chosen to visualize the levels of suffering by using the analogy of removing layers of paint from a fine antique table with the purpose of not removing all the paint, but discovering how many colors had been applied to provide the final patina. The bottom layer of color may have little resemblance to the final project, but in a particular light, you can see a glimmer of the color shining through. Each subsequent layer adds to the total illustration in various ways and for different purposes. The top layer of color represents the understanding of

the physical aspect of being with physical pain the most obvious sign of suffering. The literature stresses the importance of differentiating between physical pain and suffering (Gadow, 1991; Kahn & Steeves, 1986; Morse, 2001). This important point is acknowledged by Claire when she speaks of patients riddled with intense physical pain and, with all measures to help exhausted, she must simply be present and allow the patient to experience this part of their journey and hopefully make some meaning of it. Florence and Gwen both give accounts of signs and symptoms of physical pain, which they refer to as common, observable and many times out of control. In addition, they are both frustrated by stoic patients who do not report any pain after surgery, when the norm would indicate that they should be experiencing pain. Early in her nursing career, Demy acknowledged that she had little empathy for drug seekers in pain and it was only after a nurse pointed out that somewhere they, too, are suffering and as a nurse we need to help them change. These narratives are examples of Cassel's (1982) premise that pain is what the patient says it is and to ignore, doubt, or belittle it, can lead to suffering.

These narratives are also illustrative of the individual nature of suffering as defined by Cassel (1982), Gadow(1991), Lindholm and EriLsson (1993), Daneault et al. (2004), and Kahn and Steeves (1986) and to which other nurses give attention as well. Claire honors a patient's need for space, one who is quiet and withdrawn, because sometimes they need to stay in that place. She explains there are little things you can do with kindness, for example bringing a cup of water and not saying a word. Hallie meets patients at their own level of spirituality and honors their individual beliefs. For Elaine, suffering takes different forms depending on where she has worked. Patients in her obstetrical-gynecological office suffer from miscarriages and abortions, just as much as those in hospitals having surgery.

The second and third layers of color used to paint the table represent the emotional and sociocultural aspects of being. In the same way addition of colors to the table changes what one

sees, as nurses begin to make a connection with the impact of suffering on more than one aspect of being, a different, more comprehensive picture of patient suffering may emerge. Ferrell and Coyle (2008), in defining the nature of suffering, wrote about suffering moving beyond pain. Gwen views depression as debilitating, especially with the pain and uncertainty of illness and the unknown of surgery. Cassel (1982) questioned whether depression is not simply unresolved suffering. Betty sees the impact of pain upon her patients' social being and how it effects their sense of dignity through lack of independence. This dependence on others for care and decision making is a threat to one's loss of self (Chochinov et al., 2002; Byock, 1994). Elaine comments that many times we forget that by listening to the emotional and spiritual concerns of a patient, we can alleviate physical pain. Benner (2004) made the point that psychological suffering can be observed through fear. This is identified by Amy in her use of personal experience with fear of surgery and how she empathizes with patients who enter same day surgery, assuming that they all have fear of the unknown, even if they have previously had the same surgery. When patients say they are not sleeping, Hallie listens to them and many times the insomnia is because of a fear of never waking up.

Florence recalls a story of a family's emotional reaction to a loved one with advanced stages of chronic obstructive pulmonary disease and how the patient tries to please the family by eating. The pattern of family interaction, acquired through learned behavior or cultural norms is demonstrated even when the patient is suffering. Gadow (1991) referred to this as the "interpersonal meaning we create with one another" (p.104). The personal meaning of relationships is synthesized in Elaine's assessment of suffering as she watches the interaction between patients and their families or caregivers for clues to suffering. An exchange of information may reveal eating patterns or independence in activities of daily living, and the

observation of facial and body reactions by the patient to the conversation may aid in helping the nurse to assess suffering.

Kelly et al. (2006) determined a negative correlation between spiritual well-being and the desire for death, meaning that a sense of meaning in life and peace may offer protection from losing the will to live. Elaine relates a personal story of a loved one who lives in a long-term care facility, she hates being there, and has lost the will to live. The family is frustrated because the health care providers just want her to eat and participate in activities and will not address her suffering. Elaine refers to this as “tiptoeing around the real issues of spiritual suffering”. Spiritual suffering is identified through behaviors, which may be characteristic of the individual (Chochinov, 2006). Amy’s patient, who was not sleeping late at night, gave her permission to pray and sing with him, and this created a bond between them that was revisited years later. In working with a man who had studied to be a priest and was in the early stages of dying, Claire recognized his pain one day when he could not find his Bible. Thereafter, she began each day by going to his house, having a cup of coffee, and reading the Bible with him.

The final layers of color have been revealed and what one sees is a relationship and interaction of tones and values that create the final effect, tying together all the layers into one. Being able to assess the impact of suffering on all four aspects of being - physical, psychological/emotional, sociocultural, spiritual – and how they interact with one another sometime requires the use of other disciplines. The use of an interdisciplinary team consisting of a physician, nurse, therapist, social worker and clergy is one of four main attributes of palliative care (Ferrell et al., 2008; Meghani, 2004). This approach best serves the patient in a crisis by being able to address many issues at once and allowing for individualized, comprehensive care (Ferrell et al.).

A few nurses spoke of the participation of other disciplines in their care of patients who suffer. Claire mentions working on many occasions with a spiritual director who offered support when she found it difficult to work with a particular patient. She refers to the team support provided in hospice care and not doing this work alone. Hallie coordinates end-of-life-care at a hospital and brings together the services of all the team members in caring for a patient in need of palliative care. Hallie acknowledges the holistic suffering of a frail little woman with advanced chronic pulmonary obstructive disease(COPD), who has lost the will to live after her husband's death. She was ready to die, yet she would not let go, would no longer take her morphine, and did not want to eat. She was afraid of meeting her dead parents in heaven, because they had treated her badly as a child. In a conversation with the woman, Hallie ties together the physical pain, emotional and social suffering, and the importance of the patient's spiritual being with one simple question, are you worried about something? One can transpose this story onto the template found on page 20 of this manuscript, provided by Ferrell and Coyle (2008, p. 13). The physiological effect is represented by COPD and the patient experiences failure to thrive. The impact of failure to thrive on the physical is not eating; the impact on the psychological being is fear of taking morphine and anger directed at God; the impact on the social being is fear of seeing her parents in heaven; and the spiritual dimension is her belief of an afterlife and her inability to resolve issues in her life, leading to loss of meaning.

The contextual meaning of suffering for a patient is an important consideration for nurses who work to alleviate suffering (Cassel, 1982; Gadow, 1991). Knowing what meaning suffering holds for the patient provides the nurse with information to develop an individualized care plan in which realistic goals can be met. Sometimes nurses are frustrated because they cannot eliminate suffering, when in fact a more realistic goal may be to alleviate suffering

(Lindholm & Eriksson, 1993). Several of the nurses in this study admit that they do not always relieve patient suffering. Amy realizes her own limitations and Betty does not know that she is able to help. Gwen has resigned herself to the situation that she cannot do it all and addressing suffering takes too much time. Amy and Florence both concur that it is important to have personal experience with the type of suffering the patient is experiencing, so that as a nurse you know what to do to alleviate the suffering.

The act of being present or presencing is a dimension of Watson's Theory of Human Caring (1997) that calls for new ways of thinking and being a nurse. Watson made the call to promote the caring-healing role of nursing that promotes relationship-centered care, especially within advanced practice nursing (Watson, 1997). Through Watson's travels and personal work experience, an expanding view of her theory transcends nursing and incorporates a global perspective, incorporating Eastern and Western beliefs, into "aspects of humanity, life, death, suffering, caring, healing and health"(Watson, 1997, p. 49). Transpersonal caring requires an authenticity of being centered upon one's intentions, and the use of reflection that allows for the ability to be present, so that caring and healing of the mind, body, and spirit may occur (Watson, 1997). Watson acknowledged that to commit to a transpersonal relationship in a caring and healing practice, "one must live it out in daily life"(p.51).

Because being present implies listening to patients tell their stories, the themes of being present and storytelling will be discussed concurrently. Heliker (1999) stated that storytelling serves five functions; bonding or the formation of close relationships; validating one's life experiences; catharsis or a safe place to express emotions, providing an act of resistance with a chance to challenge general assumptions; as an educative function in which a legacy is passed on to those left behind. Stories provide a context for understanding how nurses perceive patient suffering (Heliker, 1999). So it was for myself as I listened to the stories told by the nurses

participating in the study and the transformation of role from nurse to patient and interviewer to listener took place. The stories are powerful, searing with emotion, and resonate with an individual person's singular experience in a moment of time. Providing an additional view into the window of a nurse's perception of patient suffering, stories illustrate how authentic presence may transform both participants, the storyteller and the listener (Heliker, 1999).

Seven out of the eight nurses participating in this study tell stories about suffering, both personal and professional. The professional stories become personal stories when the nurse realizes the impact of the story upon his/her caring practice. In the end, the stories may reveal as much about the nurse as they do about the patient who suffers.

The three nurses in this study, who focused their narratives on the spiritual dimension of suffering, appear to make a connection between the assessment of suffering and the capacity to be present, which transcends nursing and allows one to enter into a caring relationship. Amy explains her ability to bond with her patients through common interests and knowledge of patient behavior, allows for deeper probing into the patient's world of suffering. Her presence is facilitated through eye contact and listening. Amy's use of the words 'synchronicity' and 'bonding' indicates that she realizes the importance of entering into an intimate relationship with the patient in order for sharing to occur. Claire, in her belief, that sometimes nothing more can be done for a patient in severe pain, realizes at this point, the most caring action is to be with the patient, to walk with them through this experience. She states that the language of silence is powerful for there are no words for this kind of suffering. Therefore, with no actions and no words, one must simply be. It was highlighted by Eifried (1998) and Puchalski (2002) that being present and listening to patients as they struggle with their suffering was important in providing a relationship where sharing could take place and meaning of the experience could be discovered. Throughout her narrative, Hallie emphasizes how she continues to try and

listen. However, she challenges herself not to think too much about what she will say, allowing her intuition and spirituality to take her to different places of the experience of suffering. She explains, "Sometimes if you get too human about it, you can talk yourself right out of it. Because it can be so uncomfortable." Byock (1994) referred to this extent of authenticity in his statement, "Ultimately, suffering is encountered one to one. If the clinician has entered into any degree of authentic relationship with the patient and family, suffering is encountered in one's mind and in one's heart" (p.9). In their narratives Amy, Claire and Hallie demonstrate the act of being present and the use of self-reflection, two of the key components of Watson's transpersonal caring relationship (1997).

Several of the nurses in the study revealed frustration with addressing suffering in their caring practice and seemed to have a need to tell their stories. The interview process may have created a therapeutic environment in which they were comfortable telling their stories, one of the five functions of storytelling (Heliker (1999). Amy and Demy recount their difficult work with addicted patients and how they struggle to try and address their suffering even when the patients do not acknowledge they have a problem. As a new nurse, Florence recalls being totally helpless when asked to care for a dying patient, because she could not answer the questions the family was asking about what was happening. She was constantly being pulled out of the room, because other patients needed her attention. She wanted to answer the questions to support them, but could not and ended up in tears of frustration. In this story everyone suffers. Byock (1994) acknowledged that "to stand within and navigate within those cold, murky water (of the suffering experience) is what we can give to those persons whose suffering is not relieved by our protocols and with our potions" (p.10). Instead of being frustrated over what she could not do, Florence may have engaged in a caring practice simply by being with the patient and family.

This discussion about frustration in not being able to alleviate suffering may be a systems problem. Lack of recognition raises the question of acknowledgement. If suffering is not acknowledged, it may not be documented. And because it may not be documented, one may assume that the needs of a suffering patient went unheeded. According to Benner (2004), comfort measures are invisible, rarely charted, and never written into a plan of care. Maybe nurses take for granted the small ways in which they provide comfort and, therefore, do not realize the type of care they provide. Indeed, the level of awareness of patient suffering by nurses needs to be raised or as Watson (2001) so aptly expressed “ a different consciousness and a mindful intentionality about their (nurses) values, theories, and fundamental philosophy for caring-healing work “ (p.80).

Elaine is the only nurse in the study to mention attitude when she speaks of a deep value belief system that can permeate the way a nurse goes about his/her work. She defines attitude as not so much about nursing, but your presence and how you want to treat people. This enables her to address suffering in patients no matter where she is working. She explains, “my belief is that if the deep value belief system is a part of you, if it has been cultivated, you will find a way to use it to benefit the patient.” Elaine’s explanation closely resembles Watson’s idea of living a transpersonal caring practice and not just performing it. Being present is also defined in the literature by one’s attitude. Chochinov (2007) underscored the importance of nurses making a conscious effort to self-reflect upon the attitudes and assumptions they carry and how they effect the care they provide their patients. Cassell (1999) questioned the idea that presencing could be taught and further explained that being is not something you do, but who you are. This raises the question at what point do you learn the act of presence. Is presencing a learned behavior acquired while developing? Can it be taught or must it be acquired through experience?

All of the nurses interviewed for this study had a clear understanding of the caring role of nurses. They showed knowledge of the important points regarding suffering set forth in the literature, including the individual nature and deeply personal aspect of suffering; the impact of suffering on the four aspects of being, physical, psychological/emotional, sociocultural, and spiritual; knowledge of the context in which the suffering occurred and the meaning of suffering for the patient; and the importance of presence in working with those who suffer. Some nurses were able to integrate the impact of suffering on all four aspects of being into a plan of care. Given the perceived barriers as expressed by the nurses that prohibit them from authentic engagement with patients who suffer, there are some nurses who see no way around the barriers to practice nursing in any other way. Other nurses integrate characteristics of transpersonal caring into their nursing practice. The ability of the nurses participating in this study to perceive patient suffering is as individualized as the patients themselves.

CHAPTER VII

SUMMARY AND IMPLICATIONS

The purpose of this study was to explore nurses' perception of patient suffering, providing greater insight into a caring and healing nursing practice, which values a mindset of being authentic and being present in relationships with patients. In particular, the aim was to advance the knowledge base of suffering, so as to raise the level of awareness of patient suffering for nurses and, thereby, provide new meaning to clinical care. Through the use of unstructured interviews and by analyzing the narratives, nurses' impressions and feelings about suffering, their experiences in working with patients who suffer, and how they assess for suffering in a patient provided a rich and varied body of knowledge. By synthesizing the data from the interviews with the literature review, a complex and cumulative picture of suffering and what is required by a nurse to commit being with another human being emerged.

Narrative competence, authentic engagement, and extending care beyond the basic needs of the patient, as discussed in the literature review, are illustrative of the advanced practice nurse who seeks to understand the world of the patient who suffers by engaging in a caring healing practice. An opportunity is present for nurses to redefine what it means to be a nurse and how that redefinition will effect one's nursing practice in providing optimal patient outcomes.

This study reaffirms that the participants care for their patients and many integrate a caring and healing practice into their work. It also confirms that the health care system we experience today proves to be a barrier for some who would like to devote more time to addressing the suffering needs of their patients. These aspects are fluid in nature and are by no means set in stone. Another group of nurses may report completely different experiences with patients who suffer.

The significance of presence was discussed in the literature and supported by data from several of the nurses' narratives. What remains unclear is whether the ability to be present is something that can be taught or is it an inherent quality of the individual practicing nursing care.

The single aspect of this study that has left a lasting and powerful impression with me is the critical component of the need of patients who suffer to tell their story. A patient lays in bed waiting for anyone to visit who will listen to them talk. A nurse enters the room to give noontime medications and listens with one ear and half their thought. With a thousand tasks to do, the patient's story is cut short and the nurse hurries off to attend to other patients. The patient's story is a way of putting into words, that which cannot be expressed. Their story gives meaning to their life that extends through and beyond the suffering they experience. My hope is that anyone who reads this study, would know that for those who have no one to tell, these words have given voice to those who suffer.

Implications for Nursing Practice

Implications for nursing practice may begin with individual nurses using self reflection to assess the degree to which they implement care for their patients who suffer. Nursing leaders are in a position to encourage their staff to integrate the characteristics of a caring and healing practice, as articulated in the literature review, into their work, and allow time necessary to be present with patients. By using data reflecting positive patient outcomes relating to the reduction of pain, the alleviation of suffering, and meeting patient needs, nursing leaders can provide justification for reducing nurse's productivity when acuity levels are high. This would provide nurses with the opportunity to integrate a caring and healing practice into their work. Nurses must also be encouraged to incorporate comfort care into a patient's care plan and to provide full documentation of measures taken to comfort a patient who suffers.

Implications for Nursing Education

The biggest challenge for nursing is to mitigate the disconnect between nursing education and suffering, as the literature strongly emphasizes a need in medical and nursing schools for education in end-of-life care, death and dying, palliative care and pain management, all of which represent a critical knowledge base for the caring of patients who suffer (Ferrell & Coyle, 2008; Cassel, 1982; Meghani, 2004; Teno et al., 2004; Weigel, Parker, Fanning, Reyna & Gasbarra, 2007). Several nurses participating in this study reiterate what is written in the literature. Are these domains of nursing to be learned only through experience, an intuitive component of proficient nurses? This study illustrates a critical need for education in current pain management and caring for a dying patient.

Implications for Future Research

There were only three reference in the literature reviewed to cultural beliefs (Cassel, 1982; Ferrell & Coyle, 2008; Ferrell, Levy, & Paice, 2008). More emphasis needs to be placed on the importance of cultural and religious beliefs and rituals and their effect on the patient who suffers.

The participants in this study had a range of years of nursing experience and a variety of perceptions of patient suffering. What is not clear and needs additional research is the impact of nursing experience on how a nurse perceives suffering in patients. Also important to be explored is the impact that personal experience with suffering by a nurse has on the nurse's ability to perceive patient suffering.

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APPENDICES

APPENDIX A

Letter of Consent for Research Project

How Nurses Perceive Patient Suffering

Date:

Email:

Dear

I am a nurse in the masters' program at the University of New Hampshire (UNH) and for my thesis have decided to explore nurses' understanding of patients who suffer. The study will be conducted through a face-to-face audio taped interview of 30-90 minutes at a place that is convenient and private for you. I will also be taking notes as we talk. Your real name will not be used throughout the study to protect your privacy and assure confidentiality of information. The possibility exists of strong emotional reactions as you reflect upon your experiences with suffering. You may choose to withdraw from the interview process at any time. The possibility also exists that you may discover something new and wonderful about yourself or others. Also, your participation in this study may prove beneficial to patients for whom you care at a future time. Information on the tapes will be transcribed and interpreted by the researcher. If so desired, you may review the transcription for accuracy.

All information, tapes, notes, and memos will be kept in a security vault at my residence with a combination lock known only to myself for a period of three years at which point the tapes will be erased and the notes and memos shredded.

This letter is a means of informed consent and by signing you agree to participate in this study as a registered nurse. Your participation in this study is voluntary. A copy of this signed consent will be given to you. Should you have any questions, please feel free to contact me at any time via email sjtanis9033@aol.com or by phone 603-778-1519. If you have any questions about your rights as a research subject, you may contact Julie Simpson in the UNH Office of Sponsored Research at 603-862-2003 or julie.simpson@unh.edu to discuss them.

Sincerely,

Sandra J. Tanis, MA, RN

_____ agrees to be audio taped interviewed by Sandra J. Tanis
name

for the purpose of exploring nurses' understanding of suffering as set forth in the above letter.

I desire to review the transcription for accuracy. Yes _____ No _____

APPENDIX B

University of New Hampshire

Research Conduct and Compliance Services, Office of Sponsored Research
Service Building, 51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

30-May-2008

Tanis, Sandra
Nursing, Hewitt Hall
21 Elliot Street
Exeter, NH 03833

IRB #: 4311

Study: How Nurses Perceive Patient Suffering

Approval Date: 30-May-2008

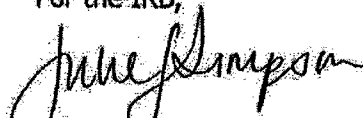
The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Exempt as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 101(b). Approval is granted to conduct your study as described in your protocol.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. (This document is also available at <http://www.unh.edu/osr/compliance/irb.html>.) Please read this document carefully before commencing your work involving human subjects.

Upon completion of your study, please complete the enclosed Exempt Study Final Report form and return it to this office along with a report of your findings.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,



Julie F. Simpson
Manager

cc: File
Tobin, Gerard