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The Cultivation and Practice of Spiritual Care Expertise in an Inpatient Palliative Care Setting

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Care Setting

by

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Abstract

Caregivers involved in palliative care seek to understand problems and challenges at end of life through research to determine the best care for patients and their families. Spiritual care is a key component of quality end of life care, yet there is a paucity of research on spiritual care in inpatient settings at end of life in nursing literature. The purpose of this study was to examine the personhood and spiritual care practices of inpatient palliative nurse consultants.

This study describes expert nurse's experience of delivering spiritual care for patients and families at end of life in inpatient palliative care settings. Expertise was compared and contrasted with Benner's (1996/2009) concept of expert nursing practice. A purposeful sample of 10 experienced palliative care nurse consultants working in inpatient palliative care in the Midwestern United States were recruited for two semi-structured interviews to produce 20 transcripts. Interpretive phenomenology was the methodology utilized to obtain narrative data and analyze the content of the transcripts. Content analysis produced a paradigm case of expert practice and an exemplar of proficient practice evolving toward expertise. The central theme of *Humbled Experts* was identified and further explored under three subthemes; *The I and Thou Relational Stance*, *Enlisting other Experts*, and the *ABC's* (*attitudes, behaviors, and communal skills*) reflecting spiritual care expertise. The study adds to the understanding of the role of spiritual care in nursing as much broader than religious care. Results of this study may add to nursing practice, theory development, education, and research.

Dedication

This dissertation is dedicated to my husband, Michael Pittroff, to my daughter and son-in-law, Abigail and Ryan Riess, to my son, Jacob Pittroff, and to my brother Thomas Simmons.

Mike, you saw this moment before I ever dreamed it. Back in the mid 90's when we both became Stephen Ministers at church; a Ph.D. came in to discuss grief and loss for our group. You said, "That lady is you, you'll be a Doctor someday, I just know it." You were right, and while I advanced my education you stepped in and supported our family, cooking, cleaning, and taking on the role of mother. You also listened to me talk and listened to me cry. You read papers and helped me express all that I held in my heart, meanwhile holding me in yours.

Abby, you have the wisdom of the ages. You told me that studying nurses in palliative care would provide the richest data possible for this subject. You intuitively knew that their story was not unlike my own, and it needed to be told. You said, "Not just everyone bothers to care for another in those ways." You were right, and perhaps this work will help foster the spiritual care that everyone deserves. During the process of doctoral education you married Ryan and I was blessed with another son. Ryan, you came into my life and this family as an adult with an inquisitive nature and genuine respect for doing something meaningful and doing it well. New Years Eve 2009, you read my method section and the Heidegger piece. You helped me clarify this section for a reader with no background in this philosophy or method. Now that is dedication!

Jake, you also believed in me and often reminded me that with hard work, dedication, and sacrifice, I could do anything I set my mind to. You perhaps sacrificed the most as you were the youngest and needed more mothering than you received, while I pursued advanced education. During this process you learned the Benner model of expertise and genuinely seem to enjoy how this relates to soccer and the education major. You never complained, and always knew in your very young, compassionate heart the importance of knowledge, nursing care, and the acquisition of skill.

Tom, we were young together and shared a unique experience of Lutheran parochial education. You inspired me in mid life with a Christmas gift of Crossan's book, *Jesus a Revolutionary Biography*. This gift was life changing for me. While reading it dashed my childlike concrete understandings of Jesus, I ultimately realized the importance of existential Christian tradition and practice. This book illuminated the hidden meaning of healing, care, and miracle while also highlighting the synonymous nature of full humanity and divinity.

I love you all and could never have completed this without your steadfast love, spiritual support and care.

Acknowledgements

v

Table of Contents

Chapter One: Background and Significance

I was sitting at the bedside of elderly woman who had suffered a massive cerebral vascular accident. Her family had decided to discharge her from the intensive care unit and provide comfort measures only. I was consulted for palliative care services and had spent the afternoon assessing her physical needs, obtaining orders to treat her dyspnea and fever and getting her comfortably settled. Her son and sister were at the bedside and were asking questions about the dying process and what they could expect in the coming hours and days. Our conversation rapidly progressed to storytelling as they both attempted to capture the essence of her 78 years on this earth, and the nature of her character. Her son, a middle aged man confessed to me how disappointed he was that his mom would not be at his graduation, to see him receive his PhD in biochemistry. I encouraged him to tell his story and he spent twenty minutes explaining his life's work and research dissertation which got rather scientific and technical in nature. About three minutes before he ended his story, I noticed that his mother had stopped breathing. Intentionally, I waited for him to finish his story, affirming his disappointment, yet reminding him that his mother had heard him and was present as he shared with us his dedication and success. A relaxed posture and smile came over him, his spirit lifted upon hearing that affirmation. I then paused, got up and calmly announced that she was not breathing, they both quickly jumped up to take her hand. I assessed her heart tones and could hear none. I announced that I was sorry for their loss and believed she had passed. Her son replied in disbelief, "What, what happened?" Her sister answered in a very kind and light hearted tone, "Oh Bob, I think you bored her to death with your PhD story." Instantly they both laughed, and then cried. I realized in this moment that perhaps I could have found a way to engage her sister in our interaction more fully. As it was, this moment was sacred for all of us. We had just spent the last hour remembering her life and imagining and envisioning the life ahead without her. It was a spiritual encounter, full of connection, reconciliation and peace. I was privileged and grateful that I had the time to get to know this family, their beloved sister, and mother if only in the last six hours of her life. Her sister and son expressed gratitude in return.

Introduction

This narrative relates to an experience I had as an inpatient palliative care nurse consultant. I chose this narrative because it exemplifies the often short time we have in an inpatient palliative care setting to provide physical, psychological, and spiritual care. It also reveals how spiritual care is very individualized and we don't always

have clear cut prescriptive ways of delivering it. We operate with cues from our patients and their families, responding with the tools we have and the skills we have learned. Those skills directly relate to the responses and care we have to offer. Spiritual care is something that nurses provide all the time in a number of different settings. In a palliative care setting and particularly at end of life, spiritual caring is much more imperative and intentional. It is a time that requires both astute and tacit skill. This study explores the phenomenon of how nurses provide spiritual care at end of life in the context of an inpatient palliative care setting and how those skills are acquired. Like any research, it may be boring to some and not prescriptive enough for others. Hopefully it will capture an audience that desires to honor the patients and families they serve at end of life by exploring and uncovering how nurses function as astute spiritual care practitioners and how these important tacit skills are developed.

Palliative Care

Palliative Care is a rapidly growing medical and nursing specialty. As Americans age they are increasingly confronted with chronic and life limiting illness. According to the Center to Advance Palliative Care (CAPC, 2004), by the year 2030 it is projected that one in five people in the United States will be an older American and many will have serious health care needs. Palliative care is considered a way to solve many of the health care issues of an aging population with acute and life limiting illness. Inpatient palliative care services and definitions vary, clarification of the concept of palliative care is revealed in the following definition from the American Academy of Hospice and Palliative Medicine (AAHPM, 2003):

> Palliative care is comprehensive, specialized care provided by an interdisciplinary team to patients and families living with life-threatening or severe advanced illness expected to progress toward dying and where care is particularly focused on alleviating suffering and promoting quality of life. Major concerns are pain and symptom management, information sharing and advance care planning, psychosocial and spiritual support, and coordination of care (p.3).

Today, institutions across the nation are designing and implementing inpatient palliative care programs to meet the needs of an aging population. According to CAPC (2006), between 2001 and 2006, hospitals offering a palliative care service increased 96% from 632 to 1240 programs. CAPC (2008) reported the American Hospital Association Survey that found of the 4103 hospitals appropriate for palliative care over 30% have implemented an inpatient palliative care program.

The definition from the AAHPM is inclusive of both hospice and inpatient palliative services. Distinguishing the differences between hospice and inpatient palliative care services becomes important for understanding the evolution of this emerging inpatient speciality. Put simply, hospice care conceptually is always palliative, however inpatient palliative care does not include hospice but may refer patients to hospice when appropriate. Hospice care may take place in the home, a hospice center or in a skilled nursing facility. Hospice services are available to persons through Medicare, Medicaid and increasingly growing numbers of managed care and private insurance providers for people with a six month or less prognosis. When making the choice for hospice, patients receive palliative care, but must forgo acute curative treatment.

Conversely, patients may choose if available, an inpatient palliative service, which does not require them to forgo acute curative treatment. This is an option for

patients with chronic and life limiting illness who experience difficulty with symptom management yet are not ready to forgo curative treatment and sign into hospice. Inpatient palliative care is also a desirable choice for patients who are acutely ill and near death, thus precluding hospice as a desirable or practical alternative, such as the patient described in narrative at the beginning of this chapter. These features are among many of the reasons people choose inpatient palliative care and why this service continues to grow as a hybrid model despite the availability of hospice care (Kinsbruner, 2005). Additionally, patient deaths occurring in institutions remain high. According to the National Hospice and Palliative Care Organization (NHPCO, 2008), early in the twentieth century people died at home, by 2008, 53% of patients died in hospitals and 24% died in nursing homes. These statistics reveal that despite the availability of in home hospice care, 77% of people die in inpatient settings. The definition of holistic palliative care combined with the statistics related to institutional deaths, point caregivers toward the imperative for improved spiritual care giving.

The importance of spiritual care is well articulated in the palliative care literature. Within the last fifteen years the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT, 1995) was designed to improve end of life care and among multiple features, highlighted the high numbers of people dying in institutions and the need for improved methods to address the spiritual needs of patients and families faced with end of life. This large multi-site study revealed 65% to 80% of people die in hospitals compared to 15% to 20% dying at home. The Institute of Medicine (IOM, 1997) also published a report on quality indicators to improve end of life care, and among many features highlighted and address spiritual

concerns. This issue is not confined to American interest alone but is an international

issue; the World Health Organization (WHO, 2002) also considers spiritual care a

critical attribute of palliative care. The magnitude of 77% of people dying in

institutions combined with increasing American life expectancy point caregivers

toward the imperative for improved spiritual care for patients and their family. This

research is focused on expert nurses who provide spiritual care for patients and

families in the context of an inpatient palliative care setting at end of life. This

research explores how nurses cultivated the skills to provide spiritual care for patients

and families at end of life and how those skills are practiced in an inpatient palliative

care setting.

Significance of the Study

Given the emergence of inpatient palliative care as a medical and nursing

specialty, research in this area is a limited but rapidly exploding field of study.

Caregivers involved in palliative care seek to understand the problems and challenges

of end of life, in general through research which provides evidence for the best care

of patients and their families. Spiritual care is a key component of quality end of life

care, yet there is a paucity of research on spiritual care in an inpatient setting at end of

life in the nursing literature. The social science literature presents an excellent

critique on the state of the science in end of life care and clearly articulates the need

for improved and increased research on spiritual issues at end of life in general

(George, 2002). A critical argument regarding the emergence of inpatient palliative

care is based on an assumption that these services would apply hospice philosophy

and principles inclusive of spiritual caring to a greater spectrum of patients. Dobratz (2005) articulates the ongoing debate as to whether or not inpatient palliative care is part of the hierarchical medical dominated model that remains oppressive for patients and families.

Most of what is known about spiritual care is drawn from the broader work of end of life research outside the context of an inpatient palliative care setting. Much of this research reviewed in the literature and presented in chapter two is related to end of life with specific groups that have only implied meaning and value within the context of inpatient palliative care nursing practice. Therefore, there is a need for an interpretive phenomenological study on the practice of spiritual care within the context of an inpatient service that would provide research based knowledge for best practice.

Sinclair, Pereira, and Raffin (2006) published a thematic review of the spirituality literature within palliative care and identified six domains present in the literature. One of the domains identified in this review involved spirituality and the palliative care professional, the authors report, "Palliative care patients have expressed attributes of professionals that contribute to spiritual well-being such as compassion, empathy, respect, self-awareness, non abandonment, and being present yet there has been a relative impoverishment of research on how professionals develop such tacit skills" (p.475). We live in a culture that keeps hidden the best of our caring practices, they are invisible and devalued (Dreyfus, 1991). Spiritual care at end of life fits into the area of caring practices that remain elusive and marginalized, perhaps due to

methodological difficulty inherit in explicating such care. Yet in doing so, we place dying patients and their family at risk of depersonalization and isolation at a time when they may be in deep need of spiritual care. Given the fact that large numbers of people continue to die in institutions, it becomes morally and ethically imperative that we examine and explore spiritual care practices in order to make safe, caring spaces for people to die in peace with dignity. The emergence of inpatient palliative care programs coupled with the call for improved end of life and spiritual care research identifies this study as important and timely nursing research.

Purpose of the Study

The purpose of this study is to better understand how inpatient palliative care nurse consultants provide spiritual care and how they acquired these skills. In fitting with a hermeneutic or interpretive phenomenological approach, nurses will be asked to describe their experiences of spiritual care giving in an inpatient palliative setting. This study will add to the body of knowledge within the direct context of an inpatient palliative care setting by researching nurses who provide care in this context, making implicit spiritual care practices explicit. The specific aims of the study are to:

1. Examine the spiritual care practices of nurses providing palliative care for dying patients and their families in an inpatient setting.

2. Discover how palliative care nurses recognize a patient or family's spiritual care needs.

3. Discover the "personhood" of the nurses providing spiritual care for dying patients and their families.

4. Examine how nurses acquire the skills to provide spiritual care and how those skills develop.

It is important to clarify that nurses described above will be palliative care nurses that are consultants for inpatient palliative care service. This study presents the thoughts and experiences of nurses in a consulting role who are actively engaged with the care of dying patients and their families. This study does not represent hospice nurses or staff nurses assigned to the care of dying patients.

Chapter Two: Review of the Literature

You keep my eyelids from closing; I am so troubled that I cannot speak.
I consider the days of old and remember the years of long ago.
I commune with my heart in the night; I meditate and search my spirit:
Will the Lord spurn forever and never again be favorable?
Has his steadfast love ceased forever?
Are his promises at an end for all time?
Has God forgotten to be gracious?
Has he in anger shut up his compassion?
And I say, "It is my grief the right hand of the Most High has changed."

Psalm 77: 4-10

Introduction

The psalmist is writing in the above quotation a lament and prayer about suffering. The circumstances surrounding this suffering are unknown. It is also unclear in the opening line as to who "you" refers to, thus leaving the reader with a question about relationship. What is clear is that the spiritual anguish is so intense; questions regarding God's justice and love are illuminated (Metzger & Murphy, 1991)**.** Nursing has long held the value of compassionate care of the dying and attends to the philosophy that caring and healing exist beyond cure (Sherman & Matzo 2001; Watson 1985). Expertise in spiritual caring involves apprehending, engaging and responding holistically to human suffering. The presence of human anguish and spiritual pain elicits a response from nurses that offers grace instead of awkwardness, hope instead of despair, and comfort instead of suffering.

The distinction between healing and curing is central in palliative care. Anthropologists and the social sciences have long held the distinction between healing and curing and between illness and disease. "Illnesses are experiences of disvalued changes in states of being and in social function; diseases, in the scientific

paradigm of modern medicine, are abnormalities in the structure and function of bodily organs and system" (Eisenberg, 1977, p.11). Addressing spiritual concerns of patients in palliative care attends to the healing aspect of care rather than curing. Spiritual care in this context is associated with the carative paradigm proposed by nursing theorists that is nursing based, patient focused, subjective, qualitative, and within the realm of the simultaneous action paradigm of patient care (Fawcett, 2005; Watson 1990). Therefore this inquiry is particularly relevant to nursing research and practice.

   The focus and purpose of this review is to evaluate the current body of knowledge regarding spiritual care for patients and their family approaching end of life. Due to the limited research in the context of inpatient palliative care settings it became inevitable to include end of life research both within and outside the context of nursing as well as an inpatient palliative care setting. Direction and discernment of future feasibility for nursing research is also a goal of this review. The ultimate goal is aimed at laying the foundation for research that improves patient outcomes and directs nursing practice that is evidence based and attends to the gold standard of palliative care. Standards of care that are articulated in the literature by Jennings (1997) as palliation and the relief of suffering, enhancing autonomy and personal control and healing or making whole.

   In preparation for this review a literature search through CINAHL, MEDLINE, and Health Source: Nursing/Academic Edition, PsycINFO and the Cochrane Library were preformed. Attempts were made to retrieve articles specifically with clearly

stated research model and designs. As a researched medical and nursing specialty, in-patient palliative care is in its infancy and draws upon a greater body of spiritually related end of life research. It therefore became inevitable to include theoretical discourse in this review in order to piece together an analysis of what is known, along with gaps in the spiritual care research. Key words included in the search were spiritual, end of life care and palliative care. The term "end of life" and "spiritual" elicited over 4500 responses. Palliative care combined with those terms help to limit the search to 50 articles. Abstracts from those 50 articles revealed 30 with relevant information on spiritual care at end of life and were retrieved for a complete read. However, some of those articles included more theoretical discussions related to end of life care and research, citing studies to augment conceptual discourse that were elusive about the quality of the research cited.

Defining Spiritual Care

According to the Merriam-Webster online dictionary (www.merriam-webster.com), the term *spirituality* derives from the Latin word Spiritus and Greek word Pneuma which means air, wind, or breath. Spirit is also associated with the animating force of life or very center of life and being. Florence Nightingale believed that spirituality was a vital force for healing. Attention to client spiritual needs, along with recognition of spiritual resources to assist clients and families cope with the challenges of life, death and illness, are as important as the physical dimensions of care (Delgado, 2005; Kelly, 2004). McSherry and Cash (2004) describe the language of spirituality and contend that "a universal definition of spirituality may be

theoretically and culturally impossible" (p.153). They purpose a spiritual taxonomy inclusive of theistic, religious, linguistic, sociopolitical cultural ideologies, phenomenological, existential, mystical, and quality of life descriptors that encompass the term spirituality. Descriptions as such enrich our understanding of the spiritual dimension of human existence yet point to the complexity involved in researching spirituality and spiritual care practice.

Key conceptual issues in this field of spiritual care relate to defining spirituality both inclusive of religious and existential domains (Tomasz, 2005). Dame Cicely Saunders, the founder of the modern hospice/palliative movement was herself a trained nurse, physician, and Christian who considered spiritual care central during end of life care. Her insights are central in the original discussions of spirituality (Sinclair, et al. 2006). However, the evolution of palliative care and global understandings of spirituality have taken on a trajectory of their own, and one that has grown inclusive of the understanding that the spirit is a dimension of personhood that is broader than religion (Delgado, 2005). In the final analysis, spiritual care may be as broad as the original definitions of spirit itself, making nursing research in this area complex but not insurmountable, yet clearly a key aspect of human existence and care.

Evolving Concepts in Spiritual Care

The distinction between spirituality and religiosity is a common source of discussion in palliative care and end of life literature. Religion is defined as a construct of human culture and meaning making that assists in the concept formation

and expression of spirituality (Chochinov, 2006). Spirituality is also described as a concept that deals with ones relationship with the transcendent questions that humans confront and how they deal and cope with these questions (Sulmasy, 2006). Apprehending these distinctions become necessary for meeting patient spiritual needs who perhaps do not have an affinity for religious language and practices yet are spiritual beings, desiring and deserving of attention, hope, meaning making, and a sense of purpose and reconciliation of relationships particularly at end of life. McGrath (2003) studied cancer survivors and hospice patients in a descriptive qualitative study. She interviewed 14 people living at home in Australia with a prognosis of less that 6 months to live and found most did not explicitly seek religious comfort in relationship to their illness. Social concerns associated with maintaining intimacy and contact with family and friends while staying connected with life and leisure were just as important to individuals as transcendent concerns. This study helps to further illuminate that spiritual care is a broad concept and dimension of life that is inclusive of religious, existential, and social concerns. Culture and demographics may also affect the contextual meaning of spiritual care and further directs spiritual care in more culturally appropriate ways.

Johnston (2006) looked at the prevalence of spiritual needs among patients with cancer and family caregivers in a cross-sectional qualitative study. The population was predominately male outpatients with prostate cancer. A self-report questionnaire was used and the Spiritual interest Related to Illness Tool (SpIRIT) was developed for this study. Data analysis included measures of central tendency from the demographic data collected. Other statistical methods included analysis of the

variance, correlations and factor analysis. This study confirmed existential aspects of spiritual needs uncovered as patients articulated the most important spiritual need as "being positive, loving others, finding meaning and relating to God." While least important were asking "why and preparing for dying" (p.729).

A retrospective qualitative analysis of 35 patient deaths was conducted in a Swedish hospice to determine the formation and development of a program and model of care for dying patients. The model of care addressed six aspects of care including, symptom control, social relationships, self image, self-determination, synthesis, and surrender. The staff were interviewed and the analysis revealed through care planning, documentation, and evaluation of quality of care that "15 patients had a very good death, 17 a good death, and 3 a bad death" (Ternestedt, Andershed, & Johanson, 2002, p.153). This study enhances the understanding that nurses perceive existential and social issues as important aspects of spiritual care at end of life.

A mixed methodological study on dignified dying was conducted via a survey through the End of Life Nursing Consortium (ELNEC) web site. Wilson, Coenen, and Doorenbos (2006) surveyed 281 nursing professionals practicing in some aspect of end of life care. The study was preformed to validate the concept of dignified dying through perceptions and view points of professional nurse care givers. Mixed methodological design was used to validate the concept of dignified dying and nursing interventions were identified that promoted it. The Fehring Diagnostic Content (DCV) model was used to examine content validity. Construct validity was

analyzed using Principal Axis factoring with oblimin rotation and Kaiser

Normalization. Cronbach's alpha coefficient for the 14 characteristics of dignified

dying rated was reported as 0.91. Spiritual and existential aspects of a dignified death

were expressed in all but two of the 14 characteristics measured. This indicates that

the nurses surveyed in this study perceive spiritual and existential aspects at end of

life a significant integral aspect of nursing care and recommendations for nursing

interventions to address these needs are included with the analysis.

A descriptive qualitative study on the experiences of nurses providing spiritual

care in an Irish hospice provided more direct information on expertise and the nursing

role in this area of practice. Nurses in this study equated spiritual care giving and

psychological caring as synonymous. An overall tapestry of care emerged that

included five themes related to spiritual caring: Nurses understanding of spirituality,

the art of spiritual caring, education and learning, challenges in spiritual care and the

elements of timing associated with spiritual care giving were identified as themes

(Bailey, Moran, & Graham, 2009). This study further bolsters the concept that

spiritual care is a complex and broad phenomenon with the need for further

investigation to develop appropriate knowledge and practice in spiritual care giving at

end of life.

<center>*Spiritual Care and Health*</center>

The evolving interest in spirituality and health has produced some unique findings

regarding coping, physical, and mental health status, and quality of life. Changes in

religious and spiritual investment were investigated in addition to disease progression

over a four year period with persons infected with the human immunodeficiency virus (HIV). Findings suggest that HIV infected individuals who reported an increase religious or spiritual interest also had a significantly less decrease in their cell differentiated glycoprotein counts (CD4) and better maintenance of their viral load (Stuezie & Fletcher 2006). In another study, 450 HIV infected patients were surveyed regarding involvement with spiritual or religious activity. Those same patients identified greater optimism, less alcohol use, improved self esteem, and greater overall life satisfaction (Puchalski, et al. 2006).

A study investigating how cancer patients cope revealed spirituality as a variable of the investigation. Examination included the extent to which cancer patients use certain coping strategies, reasons for non-use, perceived effectiveness of strategies and patient interest in trying strategies recommended. Participants were recruited from Northwestern Ontario Regional Cancer Centre and 292 outpatients completed an interview with a research assistant. Music, breathing exercises, meditation, prayer, muscle relaxation, guided imagery, and hypnosis were strategies explored in this study. Simple percentages were reported to illuminate perception and use. The study reflects that in addition to or in the absence of pharmacological intervention the most commonly used coping methods among this population were prayer, music, and religious support (Zaza, Sellick & Hillier, 2005).

Outside of the realm of end of life, the relationship between religiosity, social support, depression, and anxiety symptoms has been examined in a study on hospitalized cardiac patients and medically ill elderly patients. The results indicated

that religiousness and spirituality predicts greater social support and buffers against symptoms associated with anxiety and depression (Hughes et al., 2004). Conversely, patients who identify themselves as neither spiritual nor religious revealed worse self and observer related health and medical co-morbidity (Koenig & Titus, 2004). Research as such, points to the imperative of knowledge and skill development in nursing for spiritual caring not only at end of life but across the continuum of health.

Combating Death Distress

A two year pilot study of 38 patients with advanced cancer and 63 with advanced acquired immune deficiency syndrome (AIDS), and their family caregivers was conducted as part of a longitudinal quality of life study (Sherman, et al. 2005). The study compared similarities and differences between the patient and caregiver populations in regards to changes in spiritual well being during illness and the dying process. The spiritual well being scale (SWBS) was examined for reliability and was selected as an instrument designed to measure spiritual well being as a dimension of quality of life. The SWBS is a 20 item self reporting scale measuring two aspects of spirituality including religious well being (RWB) and existential well being (EWB). Alpha co-efficient were reported at 0.77 and higher. Chronbach's co- efficient indicated high internal consistency for all the study groups involved. The relationship between selected demographic factors including gender, ethnicity, religious affiliation, marital status, parental status, relation, living arrangement, and dimensions of quality of life was also examined using multiple regression models. The findings were reported from monthly analysis over a period of 12 months. Results highlighted

the reciprocal suffering inherit in patients and their caregivers, the importance of spiritual assessment and interventions to improve spiritual and existential well being as well as the changes associated with those factors over time.

Findings from an intervention strategy designed to meet psycho-spiritual needs were reported by Miller, Chibnall, Videen, and Duckro (2005). The group intervention was entitled, Life Threatening Illness Supportive Affective Group Experience (LTI-SAGE). The populations sampled included African American and Caucasian patients with cancer, HIV/AIDS, geriatric fragility, liver, kidney, pulmonary, and cardiovascular disease and were randomly assigned to intervention and control groups. Outcome measures included spiritual well being using the SWBS. Aspects such as depression, anxiety, death distress, illness disability, and social support were also measures of this study with corresponding tools to measure these variables. Patients assigned to the control group were sent monthly mailings for resources and patients in the intervention group met monthly for one year. Posttest scores between the intervention and the control group were analyzed using covariance. P values were set at <0.10 for significance. The results supported efficacy of the LTI-SAGE in reducing depression, increasing spiritual well being, and reducing feelings of meaninglessness and death related distress. However there is some inconsistency with the data reported in that a contradiction existed about spiritual well being not changing much after adjusting for baseline and covariance yet the P values for overall significance were met.

Lastly, in a study conducted by Miller, et al. (2002) researchers evaluated psychosocial-spiritual factors associated with death distress. Measures of death distress, physical symptom severity, depression, anxiety, and spiritual well being were used in the investigation. Cross sectional data from a randomized controlled trial were used with 70 patients who had life threatening medical conditions including cancer, cardiopulmonary, liver, kidney, HIV/AIDS and geriatric fragility. Through multiple regressions, it was found that death distress is associated with living alone, severe physical symptoms, severe depression and lower spiritual well being. These findings assist caregivers in attending to the spiritual well being of their dying patients as a way to buffer the negative effects of death distress.

Dignified Dying

Dignified dying and interventions to address and enhance spiritual care at end of life are emerging in the literature as descriptive and qualitative efforts provide more relevant evidence to assist caregivers with understanding spiritual needs of patients (Chochinov, 2002; Chochinov, Hack, McClement, Harlos, & Kristijansen, 2002). For example, a study of 50 dying patients, evaluated for their perceptions and concerns related to dignity revealed themes derived from the empirical analysis. These themes included illness related issues that detract from a patient's sense of dignity; the perspectives and practices patients use to maintain dignity; and a list of social interactions that promote or decrease one's sense of dignity (Chochinov & Cann, 2005). This study produced an analysis that was further developed into an empirically

derived model of dignity towards the end of life. The Dignity Model affords caregivers a holistic framework that may affect a patient's sense of dignity.

A follow up study integrated the Dignity Model as Dignity Therapy with a cohort of 100 terminally ill patients (Chochinov et al., 2005). Significant numbers of patients reported a keen sense of dignity, enhanced purpose and meaning, and increased will to live post intervention. Dignity Therapy involves allowing the patient to participate in their care and to tell their story. The things that give meaning and purpose to their life and the things patients need to discuss are included. The patient sessions are taped, transcribed, and edited. The finished document is given to the family with permission from the patient and represents a tangible product to assist the family with grief and help them cope beyond the patient's death. Patients report an empowerment and transcendence that reveals how Dignity Therapy may meet the existential suffering needs and spiritual well being of the terminally ill and their families.

Dignified dying may be difficult to achieve for patients without the benefit and support of spiritual care practices. Recent findings from a nationally funded longitudinal study on coping with cancer produced excellent data on advancing cancer and dying. A 343 patient sample reflected the importance of spiritual care by the medical team and its impact on patient's decisions to choose hospice and decline aggressive end of life care that detracts from dignified dying and quality of death experiences (Balboni et al., 2009).

Lack of Spiritual Care and the Consequences

Lack of spiritual care and support is identifiable globally and across the health disciplines (Balboni et al., 2007). Two hundred and thirty patients with advanced cancer were surveyed regarding spiritual support and care. This cohort rated spiritual support as the second most important variable for quality of life. Nearly half of the patients surveyed reported that their spiritual needs were minimally or not at all supported by their faith community and three quarters reported the same of the medical community including chaplains, physicians and nurses. In this same study, patients who reported receiving spiritual support from either their faith or the health care community also reported higher quality of life scores. This study adds to the knowledge that spiritual care is an essential component of quality palliative care when coping with advancing illness as well as end of life.

Correlative research that involved a nationwide qualitative study in Japan investigated why bereaved family members were dissatisfied with inpatient palliative care services (Shiozaki, Morita, Hirai, Sakaguchi, & Shima, 2005). Content themes emerged and findings hinted that the lack of communication between care receiver and care giver contributed to overall family dissatisfaction. This was reflected by family perceived lack of support in maintaining hope and respect of individuality and poor psychological care for patient and family alike. Poor communication and inadequate explanations especially about the palliative care service were also identified. Interestingly, no direct investigation or correlations naming or regarding spiritual aspects of care were identified in the study. However, implications that these

needs were not met permeate the entire study as evidenced by the reported lack of respect, hope, and the poor communication and delivery of holistic palliative care services. This overarching disregard and lack of attendance to spiritual and or existential issues at end of life permeate and negatively impact the entire experience of palliative care.

A case study interview, part of a larger study of palliative care in the Netherlands highlighted the ethics associated in the nursing role through the relational narrative approach with a palliative care patient and her husband (Abma, 2005). The case presented, featured an estranged relationship between an oncology nurse and a husband whose wife was dying from cancer. The husband's narrative expressed lack of meaning, depression, and loss of hope. The oncology nurses were unable to recognize this man's emotional and existential distress. This descriptive phenomenological work highlights the ethics of palliative care as fostering open communication about the fragility of life and impending death with palliative care patients and their families. The intentionally relational and dialogical aspect of spiritual and existential care and the lack thereof is revealed in this case study.

Gaps in the Research

Understanding the spiritual needs of palliative care patients, the nature of hope, along with tools and therapies related to spirituality are beginning to emerge. Training in spirituality for palliative care providers is also emerging from the conceptual, theoretical and seminal exploratory studies done in this field (Sinclair et al., 2006). Spiritual issues in palliative care draw upon the broader work in end of life care and

research. A critical review of the end of life research points to the lack of longitudinal studies, lack of a consensus in definition of terms and neglect of conceptual and theoretical frameworks associated with end of life issues in general (George, 2002). The criticism that the science lacks a consensus of clear or concise operational definitions does not articulate or perhaps take into account the complexity, depth, or breadth of this subject. As previously discussed the term 'spirituality' is complicated to narrow into a precise definition. This criticism clearly operates from a positivist stance regarding scientific knowledge acquisition.

   It is essential to understand that scientific research and knowledge development in the positivist framework has its purpose in producing outcome based knowledge that translates to prescriptive care. Outside of what is known about pain and symptom management, palliative care in general is situated in a realm that is sensitive to the aesthetic, affective, subjective, participatory, and dialogical nature of human care. Spiritual care in this area necessitates a stance that is naturally prudent about making generalized claims about spiritual aspects of care that are reduced to prescriptive understandings of how we care for patients and families faced with end of life issues. In my assessment, the lack of quantitative data in this area is reflective of a sensibility about the dangers and pitfalls of prescriptive end of life spiritual care that potentially reduces people to things. Additionally, designing studies that apprehend the clinical setting of such an intensely personal time for patients and families adds to limitations of research in this area. Yet as care providers we continue to be challenged by our patients and families who seek and trust our care, particularly at this most vulnerable stage of health and illness. Therefore turning to a hermeneutic phenomenological

inquiry regarding the practice of spiritual caring may illuminate and expand our understanding of expertise in this area of nursing practice. This inquiry may further assist in conceptualizing spiritual care and draw from the larger work of theorists who clearly describe the therapeutic and caring role of nursing, yet whose voices are nearly absent in the spiritual and end of life care literature.

Theory Informing Spiritual Care

Many theorists inform the practice of spritual care yet are absent in research designed to describe or examine it. Roter (2000) sheds light on the importance of theory by extrapolating the work of Paulo Freire, in writing about therapeutic relationship and patient decision making. She claims that patient participation in the medical visit's dialogue contributes to problem solving and facilitates patient confidence and autonomy. Freire (1983), a critical social theorist whose work contributes to education, politics, and health care describes the ability to liberate people from oppressive forces through a participatory dialogical approach. Freire also reinforces the idea of contextual learning. In his assessment and observation of marginalized and vulnerable populations, a person learns not only content but also learn dynamically by what they experience in context. A passive, dependent context further reinforces helplessness or powerlessness.

This participatory concept is easily translated in health care. Patients who are marginalized and oppressed by their illness and disease may also learn dependency and helplessness if treated as passive and dependent consumers of care. Conversely a person treated for illness in a participatory, dialogical context, and free to disclose

and reflect, engaged and encouraged by intentional and deliberate care providers may feel empowered. They may want to tell their full story or describe their full experience with care providers who affirm their self worth and self knowledge and in this way care becomes emancipatory. According to Freire (2001), this process assists in activating a self consciousness which empowers the learner, or in health care, the patient toward the unfolding of social analysis of a situation and joint problem solving toward health promotion and healing. As people take action regarding their situation they meld together reflection and action and this makes transformation of the status quo possible. This theoretical understanding assists palliative care providers with apprehending the existential aspects of illness that remain oppressive yet may be transformed by involving patients with making choices, taking control and responsibility for health care options and decisions. A participatory dialogical approach for patients and families at end of life embodies an existential and spiritual stance that makes possible a transformation and transcendence from the oppressive forces of illness and death.

   This kind of intentional, deliberate, participatory, and spiritually inclusive care is also captured directly in nursing literature and theory, in particular the essence of Jean Watson's theory of human caring. Her theory is associated with the simultaneous action world view attending both to the science and art of nursing. Watson (1985) explains the concept of a transpersonal caring relationship in that,

> transpersonal caring transactions are those scientific, professional ethical, yet esthetic, creative, and personalized giving–receiving behaviors between two people (nurse and other) that allow for contact between the subjective world

of the experiencing persons (through physical, mental, or spiritual routes) or some combination thereof (p.58).

Watson captures the essence of caring as relational, interpersonal or a transpersonal process or transaction. She also attends holistically to the realm of mind, body, spirit that is essential for holistic palliative care. Attention to spiritual elements of care captures this kind of caring model. Freire and Watson are examples of theorists who attend well to the participatory, relational, interactive, transformative aspects of human care that are inherit in spiritual care, yet as theorists they are underrepresented in the end of life research surveyed.

Marginal representation of theory is also present in the medical literature. A medical study alluded to a theory developed by Ellison on spiritual and existential well being (Miller et al., 2005).This group based intervention was intended to foster sharing and learning about the spiritual, emotional, and psychosocial aspects of living well while dying. The intervention was designed not as formal group therapy but as a response to the researched and documented need for improved psycho/social spiritual/existential care at end of life. The published results claimed consistency with Ellison's conceptualization of basic human needs regarding intimacy, sense of belonging, satisfaction with oneself, and sense of meaning and purpose in life. Ellison's theory was not presented as a theoretical framework guiding the study but was merely referenced for legitimacy and congruency with the argument and rationalization for the study. Therefore an assumption about the relevance of Ellison's work was implied but not explicit in this publication.

In another study where the emphasis was to branch out from the religious side of spirituality and include more secular and existential aspects of spiritual care, Ellison was referenced as being too Judeo-Christian for some of this work (Tomasz, 2005). Ellison was also noted in the nursing literature as a means to measure spiritual well being for older adults and was mentioned as the author of the Spiritual Well Being Scale (SWBS). This scale was utilized in the study to reveal the importance of spiritual well being in a small community sample of predominately white Baptist participants in southeastern region of the United States (Isaia et al., 1999). Again Ellison's theory was not well articulated in the publication. The general finding of theorists and their merely implied meaning in the palliative care and end of life research is consistent with the former findings that conceptualization and theoretical frameworks are poorly articulated in the end of life research.

Value of Current Knowledge

Much of the research reviewed related to end of life or specific groups have only implied meaning and value in an inpatient palliative care context. Some of the interventional data is illuminating and thought provoking for planning care that help meet the spiritual and existential needs of palliative care patients. The most valuable knowledge I can glean from these studies is that spiritual needs are broad and include much more than religious concepts and constructs. Spiritual needs are also dynamic and change in particular contexts as evidenced by the differences revealed among the settings that some of these studies represent. It is also evident that spiritual well being of patients and caregivers affects and is affected by other aspects of care, including

physical and psychological symptoms as well as social needs and functioning. This at times muddies up the research and takes on so many variables that it is difficult to discern the rationale sense of the questions being asked which further reinforces how difficult it is to control for these variables with traditional empirical study design.

What is clear throughout the literature is that spiritual care is an important aspect of palliative care at all points in the illness continuum and especially near end of life. Engaging patients in dialogue about their goals, wishes, hopes, fears, grief, and disappointment are all important ways to provide hope and empower patients with a voice and stance that permits participation in their care. Offering tangible products that engage the reality of illness and work of dying but allows the patient the opportunity not to be defined by their circumstances, as demonstrated with Dignity Therapy is hopeful for meeting the spiritual needs of these patients near end of life.

Most of the research discussed in this review is qualitative work which is helpful in clarifying definitions and producing a focused analysis for further evaluations. Interpretive phenomenological research on the practice of spiritual care in an inpatient setting further illuminates how nurses function as astute and tacit spiritual care providers. As nurses described their experiences and I immersed myself in the data, themes emerged that articulated the phenomena under investigation. From this study concepts may be defined and new theoretical notions may be developed for future study. Conceptual models and research questions are often derived from qualitative and descriptive works. It is also possible from these concepts to purpose a

practice theory of spiritual caring to further define and guide nursing practice, research, and education, thus helping to bridge the gap in end of life research.

In addition to the review of research on end of life care, a review of the concept of expert nursing practice becomes important to this study. The following discussion presents an exemplar of expert clinical nursing practice described by Dr. Patricia Benner in dialogue with how this concept translates and is portable and appropriate for describing inpatient expert spiritual nursing care practice.

An Exemplar of Expert Practice

Patricia Benner is a well known nursing scholar who has published numerous books and articles, among her most notable contributions to nursing education and practice includes her phenomenological research on the levels of skill acquisition in nursing practice. Her text, *From Novice to Expert* is famous and institutions across the globe have incorporated her findings as a means to evaluate and measure nursing competency. This text presents a model of skill acquisition with five corresponding conceptual levels; Novice, Beginner, Competent, Proficient, and Expert (Benner, 1984). The expert level is the conceptual and descriptive level of interest for this study. Benner acquired much of her insights from studying nurses in an intensive care setting and utilizing interpretive phenomenology as study design and method. My goal for examining her work on expert practice is to evaluate its portability and relationship for examining the cultivation and practice of spiritual care expertise in an inpatient palliative setting.

To summarize, Benner, Tanner and Chesla (1996/2009) articulate the shift from a proficient level of practice to the expert level as dramatic with discernable qualitative changes in what the practitioner is able to see. Proficient practitioners are able to read a situation but still must think about what to do. They must rely on reason and deliberate meditation for problem solving. Conversely expert nursing practice is characterized by intuitive links between seeing relevant issues and acting upon them without deliberation. Performances are fluid and nurses operating at an expert level rarely use recognition and assessment language. They do not see patient problems in a separate way. Organization, task completion and priority setting do not show up as focal points in expert nursing narrative accounts. Uniform emotional involvement is not standardized; expert nurses reveal emotional involvement with patients and families as dependent on their needs. They focus on the emotional needs of others as they present yet do not overly emotionalize caring. Expert nurses practice with mature practical knowledge and caring practices that attend to human concerns for protecting patients from vulnerability, easing suffering and preserving human dignity. Benner organizes the description of expert practice into five domains: Clinical grasp and response based practice, seeing the unexpected, embodied know-how, seeing the big picture, and agency (Benner et al., 1996/2009).

Clinical Grasp and Response Based Practice

Benner et al. (2009) describes clinical grasp and response based practice in terms of nurses needing time to "get settled" (p.142), meaning when assuming care of a patient for the first time the nurse gets a sense of who the patient is, the patient's

pattern of responses, and the immediate demands and concerns in the situation. This grasp takes into consideration the immediate past, the present, and the possible future course of events. Benner cites an example of a nurse preparing a patients family for what to expect in the immediate situation of a patient returning from the operating room from bypass surgery. The nurse's narrative takes into account the patient's history, current progress, problems, and complications. The nurse utilizes this information along with experience to prepare the family for what to expect and to connect with them. Connecting with families and creating a caring space for families to comfortably be together may include changes in the physical environment that minimize the effect of the institutional environment.

   To translate this aspect of Benner expert model to spiritual care expertise in a palliative setting at end of life flows easily. Getting settled involves knowing the patients history and illness trajectory along with the current situation and complications. For example knowing a patients medical history and how near to end of life they are takes into account their physical condition, level of consciousness and if they are eating, drinking or being artificially maintained, or if pain or other symptoms are an issue. These features assist the nurse in developing a rapport with families and explaining to them what to expect. Preparing and promise keeping are elements that attend to the spiritual needs of patients and families near end of life. Preparing the family for what the dying process is like and how the situation will likely progress along with promising patients and families the patient will not experience physical distress based on careful symptom management and the appropriate use of pharmacological agents, aids the family and patient with

confidence in their care and care provider. This opens a clearing for families and

patients to articulate all they have been through and how they as a family have

arrived at the point that confronts them. This connecting further assists patients and

families with encouragement and confidence that they will not be alone and will be

supported with compassion and confidence. This provides patients and families with

the emotional strength and encouragement to exist in a situation beyond their

control with courage, that however challenging it is to pass from life to death or to

let go of a loved one, getting through it is not insurmountable.

Embodied Know How

Another aspect of expert practice that Benner et al. (2009) described is

"embodied know-how" (p.149), which is simply fluid skill performance. It is

thinking in action and is not reflective, but coordinated through the senses in an

engaged response. This kind of response is possible through learned habitual

responses from previous experiences (Benner et al., 1996/2009). An example of this

could be any skill an experienced nurse performs such as taking a blood pressure,

bathing a patient or performing any skill without reflective activity. The nurse is just

in flow, thinking does not occur unless a crisis presents for instance broken

equipment. At the expert level even in a crisis one takes minimal time to react. The

ability to skillfully react under pressure is an example of embodied know-how and

is linked with judgment.

Benner et al. (1996) gives an example of newborn resuscitation and adds that the

expert nurse also adds a component of teamwork and synchronizing one's own

response with other members of the team as part of embodied know-how. This also

includes preparing the environment and recognizing the skill capacity of others in

the health team and allowing for shifting of roles and functioning depending on the

level of other team member's expertise. Simply stated, embodied know-how

includes knowing what to do, when to act, linked with knowing what is needed. It is

a fluid action where means and end are essentially combined (Benner, 1984;

Dreyfus & Dreyfus 2009).

In thinking about how this translates to spiritual care I realized that capturing

embodied know-how is more difficult because often it is unarticulated in the context

of an interview, it is often taken for granted at the expert level. Careful probing of

interview questions was required to uncover this in the context of an interview (See

Appendix D). Cues related to this aspect of expert care may be identified with

narratives that depict the communication or eliciting and orchestrating the expertise

of the entire health team for successful care and this relates to the next aspect of

expert practice which is seeing the big picture.

Seeing the Big Picture

According to Benner et al. (2009) expert nurses characterize their clinical

understanding as "seeing the big picture" (p. 151). This goes beyond the immediate

situation and encompasses a sense of the future possibilities for patient and family.

This expanded horizon goes beyond the individual patient and families and is

inclusive of all others assigned to the nurse for care. Sensing the needs of other

patients and the capabilities of the nurses they may be assigned with on any given

unit permits a vision of when greater expertise may be required. Heightened awareness of the needs of others and the sense of responsibility in supporting less experienced staff are all part of "big picture" skill acquisition and characteristic of expert practice.

In my experience as a palliative care provider I have had the case where a man was dying from AIDS, and prior to his death, he had suffered numerous social and functional losses including bowel and bladder function, and paralysis of his legs from a neurological infection. He became quite controlling with members of the staff on the hospital unit. His behavior escalated to the point that he would get into arguments with some of the nurses managing his care. I remember myself being challenged by this man as he would persist in telling me every move to make regarding his care. In seeing the big picture, I realized his effort to control was all he had left in his life. He was losing control of everything in his life that mattered to him. Control over the staff was an effort to maintain or recover some aspect of control. So, I graciously acquiesced to his demands. I explained to the staff my assessment of his behavior hoping that they too could see beyond the immediate situation into the big picture of this man's losses and his fate. This helped to manifest compassion for someone who was difficult to care for. Once the nurses understood the dynamic of his behavior, they stopped resisting him. In time, his demands waned and he was able to grieve the losses that he was experiencing in more self satisfying ways. His dignity was being threatened by behavior associated with his losses and conflicts including turmoil with the staff. Restoring and

maintaining his dignity was integral to spiritual care and this transformation became possible by seeing the big picture.

Seeing the Unexpected

Nurses functioning at the expert level also have practical knowledge and expectations with certain patient populations. This skill continues to develop as practitioners gain experience and satisfaction from seeing the unexpected. When a nurse senses he or she does not have a good grasp, clinical evidence is sought out to sort out the unexpected situation. The previously described skills of clinical grasp, practical know how and big picture understanding sets up the possibility for noticing when situations are not going according to plan. Benner cites an example of a nurse picking up on a congenital anomaly during a feeding episode with a newborn as seeing the unexpected in a clinical setting (Benner et al., 1996).

Spiritual care at end of life also includes the skill of preparing for the unexpected. This could be exemplified when dealing with families that are difficult to connect with. Patients and families, that for whatever reason, are not coping well with what is happening and could be manifested in socially isolating behaviors such as anger or withdrawal. Rather than viewing this as personal or professional failure expert spiritual care includes allowance for coping in all the ways it manifests expected or unexpected. This includes accepting people where they are, allowing time and space for coping, and creating safe and comfortable places to cope. When appropriate, effort might be made to engage and discuss feelings or behaviors. At some point it may help relieve tension or anxiety by getting a family member in a

more tangible aspect of the loved ones physical care to promote a sense of control and contribution from the family member. This might also require the expertise and support of other members of the team including chaplain or social worker. Expert practice in spiritual care recognizes the hallmark need for connectedness and when barriers to connection present, expert nurses respond with effort, creating possibilities and bridging gaps between patients, families, and staff.

Agency

Benner et al. (2009) goes on to describe the possibilities of moral agency created by the expert nurse as they acquire skills of clinical grasp, embodied know-how, and the ability to see future eventualities in clinical situations. "Moral agency is linked to seeing, doing, and being with others in respectful and caring ways" (p.157). Benner articulates the requirements of moral agency as excellent moral responsiveness and a vision and dedication to excellent clinical and caring practices. Agency includes the nurse's ability to identify relevant moral issues in particular situations through perceptual acuity. The skill of embodied know-how with skillful engagement and respectful relationships with patients, families, and co-workers, and the ability to manage technology by preventing technological intrusion and respond in a timely fashion encompass the expert practice of agency.

Three subcategories within agency and the skill of involvement are also described and place emphasis on the relational aspect of the care. Expert nursing narratives that illuminate the skill of involvement focus on the helping role and the strengths of others, be it patient, family or entire health care team rather than self

needs. The suffering, vulnerability, and demands of care dictate the nurse's level of involvement. This relational aspect of expert practice permits higher levels of advocacy and is demonstrated in the narratives in examples of how nurses demanded care or system changes in order to provide more equitable caring. Nurses describe a personal or emotional investment at expert levels of practice (Benner et al., 1996/2009).

Additionally managing technology, providing it safely, and the appraisal of its use is considered part of agency. Benner provided nursing narratives that depict expert levels of practice within this realm and deal with justifiable heroic care and excessive futile interventions that prolong suffering and dying. The critical appraisal of technology by the expert nurses in these narratives take place within the context of critical care nursing. Expert nurses are able to critically evaluate when technology is harmful or futile and are sensitive in rendering it less threatening to patients. They know the difference and can act as agents to enlist physicians and other members of the health care team in seeing that the patient's wishes are maintained (Benner et al., 1996/2009).

Lastly Benner describes working with and through others as part of expert care and agency. This aspect of expert care involves nurses that take strong positions with others be it other nurses or physicians in marshalling responses to get what they believe patients want and need (Benner et al., 1996/2009). Expert spiritual care at end of life embodies agency. We are all social, historical, and relational beings and palliative care at end of life involves preparing human space for dying. Spiritual

care at end of life expresses the dignity, value, finitude and unity of all humankind. Every signal aspect of care is predicated on the trust and fidelity experienced in and through the caring relationship. This relationship has moral, ethical and spiritual dimensions. As expert nurses are recruited to the welfare of others, we engage integrity to the core of our "being." We assume a posture or reverence and respect of others that engages truth. This truth in agency assists patients, families and even we as caregivers into a self transcendence and "letting go" of the control and power we feel from any certainty offered in life. We walk in loving, gracious, mystery with others as they journey from life to death and perhaps the truth of love and satisfying relationship experienced through agency becomes enough for us all.

Chapter Summary

Nursing research within an inpatient palliative care setting is virtually non existent and the medical research is just beginning to emerge and heading in the direction of randomized control trials for interventional studies. The studies discussed in this chapter are difficult to generalize specifically to inpatient palliative care and represent a broad spectrum of patients and demographics. Definitions regarding death and dying remain illusive but there is a consensus about spirituality as a dimension of personhood much broader than religion being shared and discussed in the literature. Methods to engage and interventions that address spiritual needs are starting to emerge. Research on gender differences and spirituality is hinted at but lacks refinement. Family and informal care giver needs assessment and methodologies are also underrepresented in the literature. Studies continue to be weak in regards to

operational definitions and theoretical frameworks but some seeds are presently taking root. The relevant information reveals that the field is wide open for investigation.

Nurses in a palliative care setting often provide the non medical interventions and alternative therapies to assist people deal and cope with end of life. Nurses also spend more time with patients and families at end of life than any other discipline. It therefore, becomes imperative that spiritual care be implemented well. The literature on spiritual care at end of life and the concept of expert practice with associating exemplars, informs the nurse of the importance of astute and tacit skill in providing a sophisticated level of spiritual care for patients and families at end of life. The opening of this chapter began with a lament and prayer about suffering with more questions raised than answered. Examining the phenomenon of how inpatient palliative nurses provide spiritual care at end of life further illuminates the essence and experience of expert spiritual caring. It helps to answer the questions of patients and families who are experiencing intense spiritual and existential pain by impacting the knowledge base of care providers who hear the cry and desire to respond effectively to meet those needs.

Chapter Three: Methodology

I shall be telling this with a sigh
Somewhere ages and ages hence
Two roads diverged in a wood, and I
I took the one less traveled by,
And that has made all the difference

Robert Frost

Introduction

This selection from Frost is interpretive, for me it captures my journey in nursing

and desire to explicate spiritual care expertise in nursing practice. It also captures

the distinct difference that lies between a quantitative and qualitative route in

nursing research. It does not elevate one road over the other but merely reflects a

choice. Choosing a qualitative route became clear based on my research questions

and study aims. This design definitely has made all the difference for me and I hope

my study will inform and impact other nurses. A description of the methodological

procedures including my fore structure and assumptions, recruitment of participants,

data collection, ethical considerations, data analysis, study strengths and weaknesses

are also provided in this chapter.

Interpretive Phenomenology

Interpretive phenomenological studies are grounded in philosophy, and in

particular, a philosophy that stands in contrast to traditional modern scientific

method. Traditional scientific method emerged from the time of the Enlightenment

and held assumptions based on Cartesian rationalism and empirics. Thomas Kuhn

(1962) challenged the prevailing assumptions of a value free, wholly objective

science in *The Structure of Scientific Revolutions.* However, Cartesian rationalism

and its related empirical methodology have dominated Western scientific thought since the mid 17th century. The empirical rational tradition is focused on epistemological concerns for objective absolute truth and causal relationship. Cartesian epistemology aims to reduce or breakdown data and distance the researcher from the subject (Guignon, 1983; Packer, 1985). This stance is taken in order to objectify the subject and cleanse the data from outside influence and the subjective and perceptual sway of the observer. In contrast the interpretive phenomenological approach seeks holistic understanding rather than the mere parts of our everyday skills, practices and transparent coping in life. The aim of interpretive phenomenology is to understand phenomena rather than cause and effect relationships. Phenomenology began as a method of scientific inquiry during the 19th century and evolved into interpretive phenomenology.

The phenomenological approach, according to Moran (2000) was introduced as a method of inquiry for the sciences in the mid 19th century by Edmund Husserl and further advanced by Martin Heidegger, a student of Husserl. Heidegger (1889-1976) is noted as one of the most influential philosophers of the twentieth century (Guignon, 1983; Moran, 2000) Heidegger's break with traditional schools of rationalism began by returning to the hermeneutic tradition and combining it with phenomenology. Heidegger's most famous work, *Being and Time* (1927/1962) unites human experience with interpretive understanding to describe human "Being." Heidegger believed that experience was already situated in the world in ways of being. By virtue of being, meaning and shared experience were describable and are at the very ground of phenomenology. Heidegger emphasized "Being"

rather than knowing and reshaped traditional philosophical approaches to human existence, being, history and time (Moran, 2000; Leonard, 1994). Heidegger's emphasis on "Being" or ontology verses knowing or epistemology offers an alternative to the subject/object, dualistic expression of human knowing suggested by Descartes. Heidegger points out, that detached observation and theoretical analysis is a form of being, it is just not the primary one. Our world is also understandable through our everyday practical engagement in the world. Therefore this approach is an appropriate research method for examining the everyday practice and skill of providing spiritual care. As nurses present narratives about caring for patients and families at end of life, they described the lived experience of providing spiritual care in concrete situations where meaning and shared experiences were uncovered and skills and practices explicated.

Forms of Being

Heidegger systemized the structure of "Being" by examining concrete practical ways humans interact in the world. He differentiated three forms of human engagement with the world: ready-to hand, unready-to-hand, and present-at-hand (Dreyfus, 1991; Heidegger 1927/ 1962; Leonard, 1994; Packer 1985). These forms are distinct yet interconnected when examining a person's involvement with the world. The first form is called ready- to-hand. This is the basic or primordial way of being in the world. This is where we as humans are engaged in the practice of every day living and are in flow. This form assumes human activity at a level of skill that does not require conscious deliberation or reflection for functioning. This is the level in which things are taken for granted, yet this is the also the form that

Heidegger noted as meaningful in relation to one's purpose and goals as ascribed by their culture (Dreyfus, 1991; Guignon, 1983). Examples in experienced spiritual care nursing practice include establishing patient and family rapport. Experienced nurses engage patients and families without conscious deliberation. They are able through experience and acquired social skill to engender trust and promote advocacy. This is the form in which being-in-the-world reveals transparent skilled coping of human beings for some purpose. This goes on smoothly, unnoticed unless something presents as a problem in which case the unready-to-hand form presents itself.

The unready-to-hand form requires conscious deliberation. For example, assume a nurse is taking a history for admission to palliative care and during this process a patient or family member becomes hostile or withdrawn. Conscious deliberation on the part of the nurse is required to problem solve the situation. In this form, people function in a practical way to eliminate the disturbance. The nurse attempts to remedy the situation by forgoing the history for the moment and with careful consideration provide some helpful gesture to address the problem at hand. This form requires conscious deliberation and reflection. The time involved to remedy the situation is dependent on the nature and severity of the problem in relation to the person's capacity to resolve it.

The third mode described by Heidegger is the present–at–hand mode. This is where activity stops and one is involved in pure abstract, theoretical reflection and wonder. This is where one examines possibilities by virtue of substances and their properties. This is the mode in which traditional Cartesian scientific theory based

research occurs. It involves a detached observer in pure abstract thought. For example, this form might involve a nurse researcher utilizing a research tool to gather data from palliative care patients in order to analyze a larger theory on grief. The proposition of a study such as this involves objective observation, detachment, and analysis.

These three forms of encountering are important to distinguish for interpretive phenomenological research. It is the primary form or the ready-to hand form that the interpretive researcher is interested in exploring. The phenomenon that exists in the every day practical experiences of being in the world is what the researcher is trying to uncover. As participants in my study shared their narratives of providing spiritual care they revealed in the context of their experiences that which related or mattered most to them. "Narrative accounts of actual situations give a closer access to practice and practical knowledge than do questions about beliefs, ideology, theory or generalized accounts of what people typically do in practice" (Benner, 1994 p. 110). Heidegger recognizes objects presented to the mind in abstract theoretical ways but he is genuinely more interested in understanding what exists in reality itself. The goal of phenomenological research is to bring to light the background or "clearing" in order to discover and reveal what "proximally shows itself" (Guignon, 1983, p.70). To be clear about the ontological world view of the person it is important to discuss how Heidegger's understanding of the person and he uses the German term *Dasein* to explicate this.

Dasein

In *Being and Time* (1927/1962) Heidegger distinguishes "being" or things with properties and characteristics and "Being" or ontological human existence. Describing an ontological world view of "Being" is complex because language and definitions are limiting. "Being" resists definition through language, yet it is taken for granted in understanding, for instance, we all know what it means to exist. Heidegger's work is a mission to elucidate that hidden, difficult, taken for granted essence of "Being". He uses the German word *Dasein* to describe human existence. Dasein literally translates in English to "being-there." This reveals that the activity of human being as actually "Being" in a context, in a shared world in which the things of this world are encountered and coping exists (Magee, 1987). Dasein refers to the lived reality of human being; it is relational and reciprocal. According to Heidegger, (1927/1962)

> Dasein is an entity which does not just occur among other entities. Rather it is ontically distinguished by the fact that, in its very Being, that Being is an issue for it. But in that case, this is a constitutive state of Dasein's being, and this implies that Dasein, in its being has a relationship towards that Being-a relationship which itself is one of Being. And this means further that there is in some way in which Dasein understands itself in its Being, and to some degree it does so explicitly (p. 32).

This statement reflects that Dasein or "Being" cannot be separated from the world and the world cannot be separated from Dasein. "Being" is a reciprocal relationship and "Being" is intrinsically bound in the world of beings, be that people, equipment, or substances. In other words humans exist and by virtue of their existence they are as Heidegger describes "thrown" or put into the relationships and objects of their world where coping exists. Van Manen (1990) refers to Dasien as the "entity or

aspect of our humanness which is capable of wondering about its own existence and inquiring into its own being" (p.176).

Inpatient palliative care nurses are absorbed in a shared world of caring for patients and families at end of life. They are situated so that the things they do in practice to provide spiritual care are what constitute their way of being in the world as palliative care providers. Certain things matter to them in ways that are unique to their nursing practice. They cope with the things in their world that are connected to being or are for the sake of being palliative care nurses. To use Heidegger's term it is in this "clearing" or background that the things of a palliative care nurse's world show up and matter. Heidegger used the term "clearing" as a metaphor to get at the concept of "Being." It is in the clearing that the things of this world are encountered. We all exist in a shared clearing or background. This activity of Dasein has three stances which includes "mattering", "situatedness", and "for the sake of" stance. In dialogue with Magee (1987) Dreyfus states,

> This three fold structure – being already in a mood so things matter, using things to articulate their capabilities, and pressing into new possibilities – is the structure of Dasein itself. In the second division of *Being and* Time this three – fold structure of being – in a situation turns out to be equivalent to the past, present and future dimensions of time itself (p265).

This structure of Dasein and human being is not static; it is continually self-interpreting. Human being and self understanding is dependent on our social, historical, and cultural reality, and this background constitutes the shared community of Dasein. We all exist in a context and are in the process of "Being." "Being" is dynamic, open and able to disclose new worlds. The concept of a shared

background and its integral part of "Being" is essential in understanding

hermeneutics and the hermeneutic circle.

Hermeneutics

Hermeneutics is the art of interpretation. The hermeneutic tradition dates back

to Greek mythology and derives its name from Hermes the Greek messenger god,

who translates divine messages from the other gods for human understanding

(Moran, 2000; Packer, 1985). The hermeneutic tradition developed across time and

was important in the study of literary works, ancient texts such as scripture, and in

the development of legal codes and the discipline of Law. The Protestant

Reformation and its concerns with scriptural interpretation and textual analysis

became the catalyst for hermeneutics to gain interest. During the mid 19th century

Wilhelm Dilthey further advanced hermeneutics, with the aim to make it the

methodology for all the social sciences (Guignon, 1983; Moran, 2000).

Heidegger's classical education combined with his reading of Dilthey, informed

his understanding of the social, historical, cultural and interpretive nature of all

human existence. Moran (2000) states,

> From Dilthey, both Heidegger and later Gadamer, take the idea that
> historically lived life is finite, and hence that all cultural understanding can
> never be absolute science. Dilthey distinguished between the *causal
> explanation* common to the natural sciences and hermeneutic *understanding*
> (p. 276).

Interpretive phenomenology embraces the notion that we cannot get outside our

world to conduct an unbiased, context free, wholly objective inquiry. The

traditional scientific method assumes that objective inquiry is both possible and

desirable. Heidegger posits that we always interpret from within an interpretive

stance. His work culminates in combining phenomenology and hermeneutics to describe human being.

This discovery involves an interpretive process that is circular; it is referred to as the "hermeneutic circle". Human being in the world involves a back and forth movement between partial meanings and a grasp of the whole. This idea was reflected in my earlier discussion on Dasein and its reciprocal relationship. The method for discovery in interpretive research is also a circular process that moves back and forth with the text and contains a pre- understanding or fore structure of the whole. Heidegger though, distinguishes hermeneutics as more than just a technique for uncovering meanings in a text. Rather hermeneutics refers to Being itself, in that we all live our lives toward an inherent understanding of what it means to be, we as humans are constantly self interpreting our world. For Heidegger and the researcher, hermeneutics is a more rigorous and explicit type of progression toward a deep and clear understanding of that which makes up life itself (Guignon, 1983; Packer 1985). Given the nature of the hermeneutic circle and "Being" itself, it becomes essential to name my pre understanding of spiritual care expertise in an inpatient palliative care setting.

Fore structure and Assumptions

All study of phenomenon is interpretive and perceptual; it can never be absolutely true or correct (Patton, 2002). Interpretation of phenomena is dependent on the perspective of the researcher as well as the participants' and these perspectives are always social, historical, and contextual. Fore structure is the pre-understanding a researcher brings to the situation based on language, family and

culture (Heidegger, 1927/1962). Interpretive researchers reject the notion of bracketing or setting aside pre-understanding. A neutral or objective stance is impossible in interpretive research. It is my pre-understanding of what it means to be an inpatient palliative care nurse and to provide spiritual care at end of life that permits me to arrive at a baseline understanding of this phenomenon. My fore structure is always present when I enter into the world of dialogue with the participants of my study. This includes both shared and uniquely different experiences of providing spiritual care from the participants of this study.

I am a white female, middle-age, Christian, nurse educator and former in patient palliative care nurse consultant. In addition to my nursing education I have a seminary education with a Master of Arts in Pastoral Studies. The formal study of scripture afforded me the opportunity to study hermeneutics and textual analysis. This skill was of benefit when examining the written transcripts and analyzing the data obtained from the interviews. My Christian faith has evolved over my lifetime into an existential practice of the beliefs; values and vocation inherit in Christianity. I do not however believe that the value of human caring including spiritual care is limited to a Christian world view. Caring practices have the capacity to be revealed both within and outside the context of religious language and practice. The important thing to me is that care of the human spirit actually exists, in whatever language, culture or meaning making system it originates from. My desire to explicate spiritual care stems from my wish to illuminate the existence of such caring practices.

Prior to working in palliative care I worked for ten years in intensive care, eight years in maternal newborn care, three years in hospital administration and three years in hospice. In my practice of intensive care, hospice nursing and inpatient palliative care, I had a great deal of experience with spiritual caring at end of life. My experience afforded me the opportunity in a number of ways to engage with patients and families that reflect what I consider to be the hallmarks of expert spiritual care and practice. I learned these skills over a twenty nine year span of nursing practice in a variety of settings. I learned to name these skills with advanced education, reading and reflection. These skills have meaning and value in a number of nursing settings but are paramount in spiritual care at end of life. They include attitudes, behaviors and communal skills that are discernable and describable with the context of narratives about care. I call them the ABC's of expert spiritual care.

My understanding of expert spiritual care practice includes A) attitudes of caring that involve honor and privilege, trust, confidence, courage, compassion, empathy, respect, and self awareness. B) Behaviors include, advocacy, being present, promise keeping, acts of kindness and touch including alleviation of symptoms and pain associated with suffering and C) Communal skills that include coordination of care, connecting, communication, engagement of grief, promotion of patient and family narratives or story telling, and involvement of family in the care of their loved one. These attitudes, behaviors and communal practices are what I expected and found through this study. However new meanings that eluded me came through this research and add to my conceptualizations on the ABC's of spiritual care. Through researching gaps in the spiritual care literature and studying the Benner concept of

expert practice, I realized that research could be designed to get at an authentic understanding of how nurses provide spiritual care and how those skills develop.

I assumed that the participants of this study would be able to express their experiences through the design and implementation of this study. Phenomenology assumes that meaning is achievable by people's experience and people have the capacity to describe their concrete situations to reveal meaning. This enables others to understand and possibly share experiences. This approach attempts to illuminate the everyday practice of providing spiritual care by palliative nurses by observing them in a meaningful context. Phenomenology carries with it a number of assumptions which include situatedness, unreflective engaged practical activity, and mattering. These assumptions actually help to guide and structure the study design and methodology (Benner, 1994). I also believe and was affirmed by the participants of this study that inquiry into spiritual caring has the capacity to decrease suffering, provide hope, and empower persons undergoing loss, by providing study participants the space and time to tell their stories, articulate their experience, and ultimately assist themselves and others as spiritual caregivers.

Aims of the Study

In fitting with a hermeneutic or interpretive phenomenological approach nurses will be asked to describe their experiences of spiritual care giving in an inpatient palliative setting. The specific aims of the study are as follows:

1. Examine the spiritual care practices of nurses providing palliative care for dying patients and their families in an inpatient setting.

2. Discover how palliative care nurses recognize a patient or family's spiritual care needs.

3. Discover the "personhood" of the nurses providing spiritual care for dying patients and their families.

4. Examine how nurses acquired the skills to provide spiritual care and how those skills developed.

Data Collection and Management

Sample and Setting

Purposeful samples of ten female, experienced palliative nurses were recruited from inpatient palliative care programs existing in the Midwestern United States for participation in this study. Sample size was directed based on the understanding that saturation occurs when data become repetitive and new themes are no longer emerging. Sample size in qualitative inquiry is determined by informational considerations rather than size. The logic involved in sampling for qualitative inquiry is related to the purpose and goals of the study, types of sampling, and the skills of the researcher (Sandelowski, 1995a). The goal in qualitative research is to reach adequacy or saturation and redundancy of information (Morse, 2000). Ten participants were interviewed on two separate occasions and produced twenty transcripts with full, thick, rich descriptions of how spiritual care is practiced in an inpatient setting and emerging themes became apparent and redundant.

Registered nurses who practiced palliative care for greater than three years, and have practiced nursing in total for at least seven years met the inclusion criteria. This study was designed to locate particular nurses, situated in particular situations of caring for patients at end of life. Concrete descriptions of expert spiritual care practice that did not require reflection on abstract ideas or constructs but rather engaged practical every day lived experience became available by obtaining narratives from experienced nurses. It therefore became important to exclude nurses whose inexperience with dying patients and their families may leave them to report only abstract ideas about spiritual care rather than lived experiences. Phenomenology has it goal in investigating what is, rather than what could or should exist.

Sample and Demographics

Demographic data were obtained at the first meeting using the questionnaire found in Appendix A. A table featuring all demographic data with participant pseudo names is located in Appendix F. All female, nine Caucasian and one African American (N=10) inpatient palliative care nurses with a median age of 54.5 years and all living in the Midwestern United States represent the sample of this study. Practice settings included two urban, four rural and four suburban. The highest level of education achieved represented three masters, five bachelors, and two associate degree prepared nurses. Additional certifications included eight with Hospice and Palliative Care Certifications (HPCN/ CHPN/ACHPM), two with pain management and two oncology nurse certifications (OCN). Median household income was $80,001-$90,000 annually. Nine participants reported to be Christian

and one a Unitarian Universalist. Reports of spiritual and religious practice included

four weekly, and six daily.

Recruitment

Palliative care nurses were recruited from hospitals offering an inpatient

palliative care program in the Midwestern United States. Potential participants

received a document describing my study and the inclusion criteria. I also used

"word of mouth" to recruit participants eligible for this study. The researcher's

contact number for questions or clarification was provided. A monetary offer of

fifty dollars was given to participants to offset costs associated with driving time,

gasoline or other costs associated with meeting. One participant declined this offer.

Protection of Human Subjects

Prior to the start of the study Institutional Review Board approval was obtained

from the University of Missouri St. Louis. I obtained informed consent from the

participants to participate and publish information obtained during the study. A

coding system was used to identify demographic data, tapes, and transcripts. These

items are locked in a cabinet in my locked office along with a coding key. I am the

only person who has access to these items. Pseudonyms were used in the transcribed

data. My transcriptionist returned all digital recordings to me upon completion. Any

identifying information in the transcripts was removed or concealed. I explained to

the participants that my dissertation chairperson and members of my interpretive

review committee may review these transcripts under pseudonyms with the sole

purpose of assisting with analysis. I will provide the participants with their

transcripts if they desire. Pseudonyms will also be used for any future publications

or educational purposes such as posters or presentations. Additionally, I informed the participants of my plans to hold on to the transcripts for up to seven years, and if no publications come from this study the transcripts, tapes and demographic information will be destroyed.

All participants were treated with the utmost dignity and respect. They were informed of their right to refuse to answer any question or withdraw from the study at any time. Considering the personal nature and subject matter of this study the participants may have been confronted with concepts or memories that cause them distress. They also confronted and disclosed experiences that reflected personal grief and professional failure. Every effort was taken to frame questions and responses, including nonverbal communication that is sensitive and non judgmental. Two participants cried during different portions of the interviews, at which time, I stopped the tape and offered to terminate the interview. However, they confirmed that they wanted to continue and the interview continued.

Method of Data Collection

Data were collected over a four month period. Interviews were scheduled and took place in a mutually agreed upon location. This location was selected based on environmental compatibility with privacy, noise reduction and limited interruption. All interviews were digitally recorded and transcribed. Written informed consent was obtained prior to the interviews or data collection. Permission to digitally record all interviews was obtained at the start of each interview. An investigator demographic questionnaire was completed at the first meeting (See Appendix A).

The participants were interviewed individually on two separate occasions approximately four weeks apart. Upon completion of the second interview and analysis of the data, a participant feedback letter was sent to the participants that included a summary of the themes emerging from the data. Participants were offered the opportunity to revise information that they feel did not reflect their experience through written or personal interaction. A third meeting was offered with participants if they required personal interaction to discuss validation. However, a third meeting was not required from any of the participants of this study.

Interpretive phenomenology requires multiple interviews. The first transcript was reviewed prior to the second interview and the researcher sought follow up questions or clarification from the first interview at the second meeting (Benner, 1996) The interview guides were utilized as guides, however additional probes may have been used to explore more deeply the meaning of participant responses during the interviews. Each interview lasted approximately one and one-half hours.

Interview Guides

The demographic survey guide was completed at the first interview (see Appendix A). This questionnaire was developed by the researcher to obtain data related to; age, marital status, level of education, other significant training, years of nursing, palliative care experience, income level, religious preferences and practice. This survey was needed to accurately report demographic information on the

participants of this study in order to understand the social location of the

participants interviewed.

The historical and self awareness interview guide (see Appendix B) was used at

the first interview. This guide was designed by the researcher to get at a clearer

understanding of the "personhood" of the participant. These questions are aimed at

who the participants are and how they acquired the skills to provide spiritual care.

The nursing process interview guide was used during the second interview (see

Appendix C). This interview guide was designed by the researcher and adapted

from an interpretive nursing study done in Ireland on spiritual caring (Bailey, Moran

& Graham, 2009). This interview explores spiritual caring from a nursing process

perspective. The questions are framed from an assessment, intervention and

evaluative problem solving format. This interview guide was designed to engage

dialogue regarding nursing practice.

The expertise in practice interview guide was used during both interviews (see

Appendix D) and served two functions; the first is to elicit concrete narratives of

providing spiritual care. Additionally it was utilized to examine the level of

expertise described in providing spiritual care. This guide was piloted in the spring

semester in 2007 as part of an interpretive phenomenology class. This guide follows

the nine dimensions of clinical expertise described by Benner et al. (1996, p. 373)

with probes to follow up for richer description. The dimensions are as follows:

1. Differences in kinds of unstructured problem identification. Content selected
    for examples of optimal and suboptimal performances.
2. Awareness and use of strategies to handle changing relevance as the
    problem unfolds.
3. Expectations and sets evident in clinical performance.

4. The rules, principles, and maxims at different levels of skill acquisition.
5. The use of relevant clinical population comparisons that demonstrate the Ability to recognize similarity in the particular case with an appropriate group of similar patient problems.
6. The use of analytic verses instance oriented strategies.
7. The role of hunches or understanding without obvious rational explanation in problem identification and intervention.
8. Differences in the fund of memorable "paradigm cases" cases that stand out as teaching a new clinical understanding or recognition ability.
9. Characterization of the nature of the task along intuitive dimensions.

Data Management

Data collection included digital recording and transcription of the interviews, field notes and collection of demographic information. Field notes were written at the end of each interview. This involved taking each interview and reflecting on it by identifying the date, time, and location of the interview, and description of the room environment. Participant affect before, during, and after the interview is described along with non verbal communication not captured with audiotape. I created a reflexive journal that captured my feelings before during and after the interview (Smith, 1999). This assisted with identifying my logic, judgment and emotional reaction during the research process and improved ethical research practice (Patton, 2002). This also allowed me full dialogue and participation with the text, which assisted in understanding important issues in the research project.

Data Analysis and Interpretation

Data analysis involved coding and organization of themes. The task of interpretation was up to me and members of my committee who assisted (Maietta, 2006). The first step in data analysis was listening to the tapes and comparing them to the transcript. This helped to eliminate changes in meaning derived from the

auditory presentation of the text and the transcribed document. I then read the

transcript to arrive at general understanding of the text (Sandelowski, 1995b). I

wrote an interpretive summary of my interpretations and understandings. I

compared each transcript to detect emerging themes that presented across

interviews. Interpretive research is an ongoing evolving process that requires

immersion into the text. Benner (1994) suggests naming thoughts relative to the

research questions and naming them at this stage in preparation for thematic,

paradigm case, and exemplar case analysis.

Thematic analysis occurs by capturing the larger understandings from the data

relevant to the research questions. Comparing these understandings across

transcripts for in-depth examination and pattern recognition is highlighted.

Identification of perplexing or confusing data also occured at this stage through a

back and forth process of theme illumination and theme analysis between transcripts

and interpretive summary.

According to Benner, et al. (1996) paradigm cases are "strong instances of

particular patterns of concerns, ways of being in the world, or ways of working out a

practice" (p. 361). Paradigm cases assist in identifying ways of being, that

illuminate new understandings and meanings. Exemplars assist in describing

patterns that are similar or also in contrast with meanings, situations or experiences.

Benner (1994) states that, "Exemplars, substitute for 'operational definitions

because they allow the researcher to demonstrate intents and concerns within the

contexts and situations in which the 'objective 'attributes of the situation might be

quite different" (p.117). The use of exemplars permits the possibility of capturing

relevant meaning that may not objectively present itself in the context of the researcher's analysis. This becomes useful in capturing understanding that might otherwise be missed. This aforementioned process was implemented upon completion of the first and second interviews.

The process of identifying themes, paradigm cases and exemplars involved an analysis sets up a dialectal unity and movement between parts and whole of a person's experiences, and captures the circular nature of interpretive analysis and the hermeneutic circle. This is dynamic process that apprehends the fore structure and the data as essential parts required for understanding. To enhance the rigor of this study I sought consensual validation of the paradigm case as well as exemplars and themes from a group of interpretive nurse researchers including one of my committee members who is an experienced interpretive nurse researcher. The third and final interaction with the participants confirmed that what had been interpreted was validated as representative of their experience. This was accomplished through written correspondence with the participant. This was the final stage of analysis before final explication of findings.

Strengths of the Study

Exploring the phenomenon of providing spiritual care at end of life in an inpatient palliative care revealed what providing this care means and how nurses develop and practice these astute and tacit skills. Phenomenology is an appropriate study design choice when individuals are available and approachable for research purposes, and when others will benefit from the knowledge obtained (Streubert &

Carpenter, 1999.) Phenomenology has its aim in revealing or illuminating that which is hidden, and in that pursuit uncovering of new horizons is possible.

Adherence to rigor also strengthens phenomenological inquiry. Rigor was obtained when the participants shared their experiences fully and the researcher presented a substantial and deep description of the phenomena under investigation, in this way both researcher and participant are connected (Patton, 2002). Participant consensus of the researcher's written summary was way of validating the data. When participants acknowledged what had been revealed, written findings were validated. Rigor was also enhanced through reflexive journaling (Smith, 1999). Effort was made during the interviews to set aside assumptions and remain open to the participants own experience. Summarizing and restating understanding of participant dialogue assisted with maintaining an open stance. The strength of phenomenological study is dependent on the integrity and creditability of the researcher. This was possible by careful adherence to the study design and plan of research. This was demonstrable by maintaining careful attention to recruitment, sampling, interviewing skills, and proper use of interview guides. Careful documentation of data and careful discernment with analysis of data allowed the researcher to maintain integrity with the text (Patton, 2002).

According to de Witt and Ploeg (2006) balancing the philosophical framework with the data analysis is also a way to enhance rigor. References to the philosophical framework are in discussion with the findings of this study. Multiple interviews, group interpretive consensual validation and participant validation strengthened the analysis of data and findings, ultimately enhancing rigor and validity. All things

considered the proper implementation this interpretive phenomenology study created a holistic, critical, systematic and rigorous method of investigation whereby nursing education, research and theory development is impacted.

Limitations of the Study

All qualitative inquiry is limited from the vantage point of traditional empiric scientific method. There are no absolutes in interpretive phenomenological research. No prescriptive or causal relationships can be determined. However, understanding of the subject is illuminated, and accomplished the goal of interpretive research. Limitations based on gender, age, and demographics of participants may apply when evaluating this research. I had participants with a median age of 54.5 years old, entirely female and living in the Midwestern part of the United States.

<div align="center">

Closing

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In closing, models for palliative care such as the one defined by the American Academy of Hospice and Palliative Medicine (AAHPM) in the introduction of this dissertation provide a starting point for holistic hospital based palliative care services as more than just a comfortable decline into death. Addressing spiritual concerns in this type of service is critical if the model for holistic palliative care is to be actualized. Phenomenological research that attends to how nurses cultivate and practice spiritual care for patients and families in a palliative care context creates great possibility for enhancing nursing research, theory development, and nursing education. Additionally this research opens a dialogue that may begin to bridge the gap in end of life research and care.

Upon reflecting on the poem by Frost at the opening of this chapter, I realize that dying patients and their families are uniquely on a road less traveled. As losses culminate and death approaches, patients and families are faced with a qualitatively new way of constructing meaning and living in the absence of their loved one. The nurses who journey with them have much to offer and spiritual caring becomes paramount. In choosing to do this research, I was able to illuminate the nursing practice of spiritual care while uncovering some of the ambiguities associated with providing spiritual care at end of life for people and their families. I hope it will make a difference for everyone on this journey.

Chapter 4: Manifest Spiritual Care

I don't believe there are any such things as accidents. I think that we all manifest what we want and what we need. I don't think there is any difference really in what you feel you have to do in your heart and success, they're inseparable!...

Life is like clay, waiting for us to mold it. When you trust your own insides and that becomes achievement it is a kind of principle that seems to me is at work with everyone. God bless that principle, God bless that potential that we all have for making anything possible if we think we deserve it.

Shirley MacLaine

Introduction

We all know that accidents do happen, but the above quotation is part of an acceptance speech from the Oscar winning actress Shirley MacLaine for the 1983 film, *Terms of Endearment.* Ms. MacLaine's speech expounds on the phenomenon of success related to an acting and film career. Her Oscar was no accident; she had given her heart to her craft and cultivated expertise in acting which resulted in success. Interestingly this film depicted a family undergoing the loss of a loved one through terminal illness. In the film, Ms. MacLaine portrays the mother of a young adult daughter who is dying, and the only one in the film to engage her daughters suffering and advocate for her at end of life.

I find it fascinating that many of the nurses when interviewed for this study described their own professional success in nursing and expertise with spiritual care as stemming from a deep desire within themselves to provide the spiritual care they believe everyone deserves. The challenges and conflicts in the nurses own lives, and often the lack of endearing experiences during the death of a loved one served as the

catalyst for cultivating successful spiritual caring practices with patients and families at end of life. Today palliative care nurses manifest in practice the spiritual care their clients want and need, whole heartily believing we are all deserving of it.

This chapter presents a paradigm case with excerpts from Betty reflecting spiritual care expertise and practice in an inpatient palliative care setting. This is followed by and contrasted with exemplars from Barb reflecting proficiency evolving toward expertise in practice. All excerpts throughout this dissertation have been given a pseudo name for identification. Prior to discussing how these narratives fit with the Benner model of expertise in nursing practice I believe it is important to discuss the personhood of Betty. Her life experience and commitment to care is illuminating in terms of how her practice is informed.

Personhood of Betty

It is also no accident that Betty, an expert palliative care nurse, attends to her patients and families spiritual care needs with intention and skill. Her life world is revealing in terms of drive, motivation, and experiences that inform her ability to provide spiritual care. Betty is a fifty five year old palliative care nurse consultant with 32 years of nursing experience and 12 years of palliative care experience. She holds a bachelors of science in nursing and is certified in hospice and palliative care. Betty is currently practicing in a rural setting and is passionate about her work and the difference she is able to make in others lives. Betty self discloses how life experience, personal and family suffering, along with her own awareness of spiritual growth provide her the desire and ability to care for others.

Betty: Well, I am one of 7 children, I have five older brothers, and I had a sister who died at 18 months. I am the last, I am the baby. I come from a Lutheran background, went to church every Sunday. I would say my mother was very religious, my father was not, however, we did not talk about religion. My mother worked seven days a week, so I did not see her very much. My father was sick and died when I was 15. I pretty much was raised by my brothers. I don't really think that my upbringing…my childhood, helped a whole lot…. I think what helped the most was being out on my own afterwards. I did more soul searching after I got out of school. I think that's what formed most of my life. I've always known, from age 7, that I wanted to be a nurse. That was my goal in life. I always knew I wanted to help people, so I had a focus from a very young time. I'm very driven and I don't waiver from what I'm driven too. I think that when I got out of college I really did a lot of soul searching of who I wanted to be, because I grew up in an alcoholic family. It really shaped my life, how I wanted to live my life and how I wanted to help people… how I wanted to change, and I think that was really the biggest focus of how I wanted to lead my nursing career. So I think that was really the start on my spiritual journey.

I: So you think the major motivation for cultivating these skills is desire, you have to want it first of all?

Betty: I think first of all you have to understand it in yourself, because if you don't understand it in yourself, how would you even understand it in somebody else?

I: Exactly….Obviously you recognize yourself as a nurturer and wanted to connect with people. How did you nurture yourself throughout the years?

Betty: A lot of soul searching, a lot of talking to other people, a lot of reading. I've gone to lots and lots of conferences.

I: On the subject of spirituality and spiritual care?

Betty: Yes

I: That's great. Did your nursing education, back in the day… did it inform you of how to care for people spiritually?

Betty: No.

I: And you went to a university right?

Betty: Right.

I: So how do you think you cultivated those skills?

Betty: I think some of us simply want to do it and connect that way. I think some people are afraid. There are nurses that have absolutely no desire or want to get that close to patients or to find out what patients want spiritually, and there are others that really want to be able to do that. So I think there are all kinds of nurses.

I: So life experience, desire, understanding your own spirituality, and what that means to you. Anything else that you can think of?

Betty: Learning from my patient, which is huge if you take time to listen, they will teach you so much.

Betty informs us of the need and desire for spiritual self awareness and growth which is essential for learning to provide spiritual care for clients. Her understanding is congruent with nursing theory and research that point out that a nurse's awareness of spiritual thoughts, feelings and beliefs directly impact and influence the nurse's ability to provide successful spiritual care (Guido, 2009; O'Brien, 2008; Sherman & Matzo, 2001; Taylor 2002). Taylor and colleagues (1999) investigated spiritual care perspectives and practices among hospice and oncology nurses. This study empirically demonstrated a relationship that reflected the degree to which nurses report themselves as spiritual, also predicts their beliefs about and ability to provide such care. A nurse's likelihood of assessing spiritual needs has also been correlated with their own self reported sense of the spiritual (Ross, 1994). Betty also discloses how fear, lack of desire and inattentiveness to patients exist as barriers for learning how to provide spiritual care. The following excerpt provides a glimpse of Betty's historical evolution for improving spiritual care.

I: Okay. Any other life experiences, maybe outside of the medical community, that maybe you haven't touched on that you think contributed to your ability to provide spiritual care?

Betty: I've had lots of deaths in my family, and so probably each of the deaths teaches you something, you know. Three years ago I had a niece die of cancer, she was in her 30's, and we had long talks…long talks about spirituality, just about life and higher powers. She was very religious. But just things that people say. She asked me one time about when people come to you and say, 'if you just fight harder you'll get better,' and I keep fighting but I'm still going to die. Does that mean that I didn't fight hard enough, and why do people say that to you?

I: Because they can't handle you being sick.

Betty: That's right. Right, exactly. And her point really was so good, and how do you help other people spiritually? I said sometimes you can't yet; they're not ready to be helped.

I: Anybody else close to you…

Betty: Well the reason I started in the palliative care program is because of my brother who died.

I: Yeah, you were telling me that, and he didn't have a good death experience?

Betty: No, he had a terrible death experience. He had a heart attack and stroke, and he had not wanted to be resuscitated or to have any kind of extraordinary measures done… He did not have an advanced directive and had told me he wanted me to be his "durable power of attorney." But he was in another state and didn't have it in writing. By the time I got there they had already put him on the vent and the pump…had pressors going and so forth. His doctor did not want to stop treatment because he was from another culture, and felt it was inhumane. Even though as a family we had wanted to stop things, the physician didn't. So that made things much more prolonged and because it was on a weekend and it was past noon, his physician left and we had another physician. So we had to go to that physician, and he didn't want to stop treatment because he wasn't the primary physician. They didn't have an ethics committee when we asked to consult one. So then it ended up being that we actually had to remove the equipment ourselves because the attending physician didn't want to do it but he agreed to stand at the door.

I: Oh my, that's not well…When did this happen?

Betty: That was 15 years ago.

Betty's narrative reflects the complexity of the health care environment and how her brother's end of life care involved the care providers' unwillingness to take responsibility to uphold the family's wishes. The personal belief of the physician and perhaps fear of legality got in the way of a dignified peaceful death for this man and his family. Spiritual care was far removed from this care setting. No consideration was taken regarding how this family would cope with the lasting memory of removing the equipment that stood between life and death for their beloved brother. The physician literally stood at the door, detached and unable to advocate for this patient and family, yet unknowingly he was standing on a threshold that ultimately would give way and demand involvement for improving end of life care as the following account describes.

I: So you kind of had a vision after that, there was something you could do?

Betty: Well even after that, the 12 hours that he survived…we had two nurses. One was a very good nurse she was very compassionate and very much there to help the family go through this. We also had a nurse who was much less compassionate and focused on herself, and it just made me realize that, you know… there are two kinds of nurses…. A lot of things that we think as nurses, that we do with good intentions really don't come across to families, when they're grieving, as good intentions. The suffering that he went through was unnecessary. As a nurse, I could fight that because I had the knowledge, and I could care for him. But after it was all done and over… I lost out on being a family member to him, and I couldn't get that back…. So what happened is it just gave me the anger to want to make it better for other people so that they didn't have to go through what I went through. That anger, it pushed me to do a lot of research and look at how do we do the same thing here at work… do we really follow what people want, do we look at pain and symptom management? Do the nurses really listen to what the patients want, or do we really listen to the families? Do we give them the opportunities to have time with their loved ones? Do we really truly treat the pain appropriately? What I found out was we didn't always do that, and we could've done a lot better in many areas… and it's not always that you intentionally don't

do it… it's because you don't know how to do it. So based on that, it helped me to do a lot of research and set up a pilot program and then eventually set up a palliative care program. So good did come out of the bad.

Betty had firsthand experience with the lack of good end of life care. Her losses were compounded by the "fight" she had in maintaining her brother's wishes. The "fight" got in the way of and further created a social loss of "being a family member to him" during his last days that precluded his actual physical death. During the last hours of his life, Betty was easily able to discern genuine caring from detachment and poor communication in the nursing care they received. The tragedy of losing her brother in mid life was compounded by the depersonalization of the health care environment. This experience left Betty grieving and angry, however in time she transcended this and set out to prevent "unnecessary suffering" for others. She adopted, what theologian, Henri Nouwen (1979) coined "a wounded healer" response. Betty's own woundedness, her distress, hurt, anger and grief became a source of action to provide genuine, sensitive empathic care for others.

Betty self discloses how life experience, personal and family suffering and loss along with her own spiritual growth provide her the desire and ability to care for and protect others. Her personal life experiences, conflicts and challenges inform her practice and assist her in providing the care for others, that she believes want, need and deserve. This kind of knowing is described by Carper (1979) and more recently Chinn and Kramer (2009) and encompasses the personal, ethical, aesthetic, empirical and emancipatory ways in which nurses know and also add to nursing knowledge.

Betty's life world and desire has motivated her to become an advocate for patients and families and improve end of life through nursing practice in palliative care.

The Lens

Betty's life experience, her situatedness and things that matter to her create the very lens by which she views spiritual care. The lens that one looks at spirituality and spiritual care is vital for implementing it. As discussed earlier, the literature is clear about the importance of spiritual self awareness and understanding the broad spectrum of meaning this holds for individuals. Keeping a reflective journal during the research process assisted me with the recognition of my own lens. Not just in terms of my spiritual understandings but in terms my anticipations and assumptions about the nurses I interviewed. Uncovering bias, assumptions and just plain thoughts, prior, during and after the interviews through journal writing, greatly enhances the researcher's ability to see.

Van Manen (1990) discussed how writing in interpretive research, is a way to measure our thoughtfulness and does not only enter the research process in the final phase. He states, "Writing creates a distance between ourselves and the world whereby the subjectivities of daily experience become the object of our reflective awareness" (p.127). Reflecting on Betty's personal suffering became an enlightening moment for me during and after the interview. I reflected back on my own practice in intensive care, as a young nurse and how ill equipped I was to provide spiritual care at end of life. I remember feeling at a loss for ways to comfort when someone was dying and focused my energy on keeping things neat and clean to substitute for this

void. Professional healers however, do not just clean when in doubt. When practices

are ineffective healers do not abandon their practice but rather are drawn more deeply

into learning how to correct, improve and strengthen them (Kesselring, Chesla, &

Leonard, 2010; Dykstra, 1999). They also draw others into participation for deepened

understanding and skill while extending this to the larger community until excellent

practice is made manifest and the well being of patient and families is sustained.

Betty's disclosure brought this to the forefront of my awareness.

Betty and the other participants of this study helped me see beyond my privatized

awareness into the shared social and pervasive importance of spiritual caring inherit

in the practice of palliative nursing and nursing at large. Also, I expected as I drove

into the rural areas of Missouri and Illinois for the interviews that I would receive a

great deal of homespun religious talk regarding spirituality and spiritual care from the

nurses I had appointments with. I feared that the rift between religion and science

would potentially diminish the data I could share. However, my own preconceived

ideas about "country folk" were delightfully mistaken.

> I: Okay. First of all, I want to know, how you view spiritual care. Do you see religious care and spiritual care the same, how do you view that?
>
> Betty: It's much more than that, much more. It is whatever the patient deems as the reason for getting up every morning. It is what brings them peace and comfort. If it is religion, fine, if it is music, fine. The focus has to be whatever the patient says it is. I think the big thing was, and I think the big thing we have to work on with not only patients, but staff… is remembering that we have a tendency to think that spirituality is religion. I think we have to get rid of that notion. One of the things I do with all of my patients… is to simply ask them, what makes you get up every morning? What brings you peace… comfort, and the most joy? Whatever they say bring that into the hospital

room. Bring that into the care of every day. If that's the dog, bring their dog in. If it's the family, keep the family there. If it's a blanket, pictures, or their Bible, then that needs to be incorporated into their care.

Equating spiritual care to religious care has perhaps stifled nurses in the past from fully engaging their role as spiritual care providers. Reasons for this are many and may include the care giver, patient or families lack of affinity for religious language and practice or avoidance of the subject for fear of imposing personal beliefs. Also and justifiably so, many practitioners also view religious care beyond the scope of their practice. Perhaps nurses' efforts not to delve into issues and concerns that involve the "Divine Spirit" ultimately place the human spirit and its care at risk of being eclipsed. However Betty a practicing Christian and not dismissive of the importance of religious care sees a bigger picture and potential for spiritual care within her nursing role. She describes attending to the human spirit as finding out the meaning or purpose in her clients lives and incorporating that into their care to provide comfort. The previous narrative highlighted Betty's ability to see spiritual care as open and vast, inclusive of the nature of one's essence and being. Her desire to discover the individual meaning this hold for her clients and incorporate this into their care at end of life is related to her full awareness of the possibility for making the transition from life to death a meaningful, dignified and peaceful experience. As people face life threatening illness and end of life spiritual needs are heightened and emerge to the forefront of care (Matzo & Sherman, 2001). Betty views the inpatient palliative care role as a context for engaging individualized spiritual needs to guide the goals and plan of care. The following discussion is in dialogue with the Benner

model of expertise in nursing practice and the examination of its portability for describing nursing spiritual care expertise.

Expert Practice

Benner et al. (2009) studied 130 critical care nurses utilizing interpretive phenomenology to describe expertise in nursing practice. She distinguishes the proficient level of practice from the expert level as marked with dramatic qualitative changes in what the practitioner is able to see. She describes expert nurses as practicing with mature practical knowledge and caring that attends to human concern for protecting patients from vulnerability, easing suffering and preserving human dignity. According to Benner, expertise reflects five domains that include; clinical grasp and response based practice, embodied know-how, seeing the big picture, seeing the unexpected and agency. In part this study was aimed at looking at the expertise model and examining its portability for describing expertise in spiritual care at end of life. Betty, representing a paradigm of expertise spoke to all of these domains in describing her practice. In the context of interviewing the nurses for this study I found that these domains overlap and are not mutually exclusive. This is not in antithesis to the Benner model but actually reinforces the notion that experts develop skills that reinforce each and every other domain. At the expert level an integration of skill exists for holistic expert nursing care.

A Synthesis of Domains

Rather than deconstruct a narrative to discuss the presence of expert domain

described by Benner, I have chosen to present the narrative in its entirety. Betty is

describing a situation that reflects the existential presence of spiritual care in an

inpatient palliative care setting at end of life and reflects a synthesis of domains

described by Benner and integration of practice requisite for expertise.

> Betty: We had a 50ish year old gentleman that came to the medical intensive
> care unit after arresting in the doctor's office. He just came off the vent, and
> was brought up the floor unresponsive. He had a common-law wife and two
> daughters. I talked with the wife and the daughters and I asked them to tell me
> about the patient, and I asked them to tell me about his life, where they lived,
> what he enjoyed doing on his days off, about his heritage, what brought him
> the most joy, what his favorite smells were, what he liked to listen to….They
> told me the story that he was part Indian and that they lived on a horse farm.
> On Saturdays he used to bring in children and give them horseback rides, and
> his favorite smell was the smell of hay. He also would often go out among
> nature on his horse and take off his saddle blanket and put it on the ground
> and listen to the sounds of nature, and his flute…. So we were talking about
> how we could make his room be a place where the sounds and smell and the
> environment would be a place that the senses would hopefully make him in
> whatever ways he could partake of it, be the most comforting to him… But
> also to make the family feel that they're in a place that they feel most comfort,
> and that when they're in there, they're not seeing a body that is withering
> away, but they're seeing a man that they remember who's living life…
> someone who is enjoying the sounds and smells and the man who is taking
> part of his heritage. Someone who is telling stories, who is giving back to
> children…. When the nurses and the doctors come into the room they're also
> not seeing a gentleman who just had a stroke, but they're going to ask what is
> going on in this room, why is this happening and what's happening here? So
> we chose to bring in a bale of hay, and we put his saddle blanket on his bed.
> We had flute music playing in the background. We had his bridle in the corner
> in the room and pictures of the horses and the children playing in the
> background…. So the idea is when you walk in, you're going to see pictures
> and ask what does this mean, and why is the hay here, and each person then

can tell a story about who this man really is. You're not focusing on somebody who's dying, but you now get to know that this man is part Indian and his love was to give children horseback rides. His favorite smell was the smell of hay, and that he loved the sound of flutes and nature. That is what his life was about, and that's what his spirituality was about.

Clinical Grasp and Response Based Practice

Benner et al. (2009) describes clinical grasp and response based practice as a domain of expert practice. " When assuming care of a patient for the first time, nurses talk about needing time to 'get settled' meaning to get a sense of who the patient is, the patient's pattern of responses, and the immediate demands and concerns in the situation" (p.142). This grasp takes into consideration the immediate past, the present and the possible future course of events. The nurse utilizes this information along with experience to prepare the family for what to expect and to connect with them. Connecting with families and creating a caring space for families to comfortably be together may include changes in the physical environment that minimize the effect of the institutional environment. Getting "settled" in this narrative involved knowing the patients history and illness trajectory along with the current situation. In Betty's narrative, physical comfort is a given. However she points directly to spiritual concerns and making an assessment for implementation of this into their care. Because of her clinical grasp she immediately is able to see what the future holds for a patient who is just extubated, unresponsive, and sent out of the intensive care unit for comfort measures only. This leaves Betty a short window of time to ensure his comfort and foster connection with the family which she successfully accomplishes. Betty's clinical grasp overlaps with and informs her ability to see the big picture.

The Big Picture

According to Benner et al. (2009) expert nurses characterize their clinical understanding as "seeing the big picture." This goes beyond the immediate situation and encompasses a sense of the future possibilities for patient and family. Betty knows this family does not have time for a hospice option, time is of the essence. She is quickly able to engender trust and a relationship with this family. Her quick connection in turn allows the family to reconnect with their loved one in ways that are meaningful to them. This expanded horizon goes beyond the individual patient and family and is inclusive of all others assigned to care of this patient. Betty's expertise opens the possibility for other staff to assist with the spiritual care of this patient and family by transforming his room in such a way that promotes engagement and connection. Heightened awareness of the needs of others and the sense of responsibility in supporting less experienced staff are all part of "big picture" skill acquisition and characteristic of expert practice (Benner, et al. 2009). Betty is able to accomplish this fluidly without deliberation which indicates the form of being Heidegger (1927/1962) describes as "readiness to hand," and demonstrative of embodied know-how and skill.

Embodied Know How

Another domain of expert practice described by Benner is "embodied know-how" which is simply fluid skill performance. It is thinking in action and is not reflective, but coordinated through the senses in an engaged response. This kind of response is possible through learned practice and previous experiences (Benner et al., 2009).

This is often described with evidence by observing nurses perform physical tasks with fluidity. Spiritual care also involves embodied know that may or may not be observed through a physical task such as providing complimentary therapies. In this case Betty's intuitive skills enable her with embodied know-how to fluidly foster story telling. Her embodied relational skills in turn allow the family to become the voice for this man. Betty's embodied ability to develop a relationship and trust with this family without deliberation, skillfully sets up the possibility for providing spiritual care. Creating a relationship and environment that further shores up meaning and support during a difficult time for patients and families is reflective of expert spiritual care (Guido, 2009). Betty's clinical grasp, ability to see the big picture and embodied know also serve to assist her with moral agency by honoring this man in a caring and respectful way. The possibility for agency is created through a synthesis of the domains of expertise in nursing practice. Agency is represented in each of the accounts presented with this paradigm case. I will return to a full discussion regarding agency but first it is important to describe seeing the unexpected and how this domain is represented in end of life spiritual care.

Seeing the unexpected

Nurses functioning at the expert level also have practical knowledge and expectations with certain patient populations. This skill continues to develop as practitioners gain experience and satisfaction from seeing the unexpected. When a nurse senses he or she does not have a good grasp, evidence is sought out to sort out the unexpected situation. The previous described skills of clinical grasp, practical

know how and big picture understanding sets up the possibility for noticing when

things are not going according to plan (Benner, et al. 2009).

> I: Well what about any patient families, where maybe it didn't go as planned or you didn't quite, for one reason or another you never really made a connection.
>
> Betty: When you have a big family you sometimes can connect with a group of them but not one. One's not ready, and I can think of one family that we had… a mother who had a stroke. Everybody in the family was just so ready for this mom to die, except for one. He was so angry, so angry, and even though we talked about it and we discussed comfort measures and we discussed not feeding, and they all are in agreement, the one really wasn't in agreement, and you know, you can see it on their face…. And I remember asking this one son, you know, you seem really hesitant when we talk about not feeding her. Well I don't like it. Okay… and what's your hesitancy? I just don't like not feeding her. Okay, we talked about the pros and the cons, and the power of attorney is sitting over there…'you know, mom didn't want this so we're not going to do it.' You've got nine kids and everybody's okay about the decisions except that one. I remember how angry he was. There were fights in the hall between the durable power of attorney and him. He was so mad every day, and yet we could not get him to be comfortable with it, and that's difficult.
>
> I: No matter what you said or told him, in terms of prolonging suffering?
>
> Betty: No.
>
> I: Because he knew your agenda so to speak.
>
> Betty: Yeah. And it wasn't my agenda to get him to change his mind, it was just to get him to talk about why he was so uncomfortable, what I could do to try to help make it better, but the only thing that would've made it better was for her to get better and I couldn't do that.

This narrative depicts seeing the unexpected when dealing with families and

individuals that for many reasons are difficult to connect with. Often times despite

the clear understanding of a patient's wishes, families for multiple reasons do not

agree. This sets up an environment adversely affecting coping during end of life and

can be manifested in socially isolating behaviors such as anger or withdrawal.

Rather than viewing this as personal or professional failure expert spiritual care

includes allowance for coping in all the ways it manifests both expected and

unexpected. This includes accepting people where they are at, allowing time and

space for coping and creating safe and comfortable places to cope.

> I: For instance, the story with the gentleman who was so hard to connect
> with, that would not let you help him…when you recognize this problem, how
> does it change your priorities, does it change your priorities?
>
> Betty: I really try very hard to get everybody comfortable because I think it
> would be horrible to live with a feeling the rest of your life…or have guilt that
> you killed your parent or you didn't do everything to save their life or you
> were responsible for their death in some way. I would not want anybody to
> ever feel that way, even if they don't have the legal right to make that
> decision. I also realize that when you've got nine kids it's really hard to get
> everybody on the same page on the same day. I mean that's really difficult to
> do. Families come in at different stages, at different levels, so the sooner you
> can start talking with people before you need to make decisions the better you
> are. Some people you're never going to get there and I understand that too….
> But that doesn't mean I don't want to try to help people to get there. Now, the
> durable power of attorney was very insistent we move ahead with comfort
> measures only. But I still worked with the son every day to help him work
> through this. So yeah, he was one of my priorities, the rest of them were fine
> once the decisions were made. Their mother had what she wanted because she
> had a living will and advanced directive already made out. But the one son
> was suffering, the rest of them were okay, mom was okay, he was suffering.

   Betty is able to see the unexpected in ways that go beyond the immediate situation.

She expects that people will cope with death and dying in multiple ways and she

understands reciprocal suffering that families often display when faced with a loved

one's illness and death (Sherman & Matzo 2001; Sherman et al. 2005). Her ability to

see the unexpected in this case is related to her grasp of complicated grief in the

present and seeing the possibility for continued suffering and protracted grief for this

son in the future. She fosters dialogue and support to help a son who is currently

struggling and may continue suffering beyond the death of his mother. This again

illuminates the expert nurses' ability to see the big picture as well as the seeing the

unexpected in spiritual caring when someone is difficult to connect with related to

their coping skills.

> I: What kind of advice would you give to a beginner or another nurse in a similar situation?
>
> Betty: If she was working with me I'd take her with me and let me do the talking and let her watch, and then discuss it afterwards, how do you think it went, what would you have done?
>
> I: Just draw her in for observation. Would you give her any advice?
>
> Betty: On what I would do? No, because I'm not there, it's not my situation.
>
> I: When you worked with the family with the son who was suffering, were you informed by like things you read, what kind of made you aware that this was a piece that needed to be addressed?
>
> Betty: No. I just took care of him. I want to back track to something I told him and told the whole family. I do say this when someone has an advanced directive, I think it's wonderful that your mother was so thoughtful, she gave you such a wonderful gift, that she made her wishes known to you…that she's already decided what she wants so that you do not have to make this decision. So that you never have to feel like you did not do the right thing or ever wonder if you did enough, so you will never have to feel guilty. So I do always say that.

Despite Betty's awareness that she was unable to fully connect with one son in this

large family does not detract from the agency she maintained for all of them. Her

agency was made possible through a synthesis of clinical grasp, embodied know-how,

seeing the big picture and seeing the unexpected. Her practical knowledge and

experience is fused with perceptual acuity and intuitive skill. She understands this

skill as dynamic, as every situation is unique, complex and ever changing. This

dynamic necessitates the expert be open, in order to intuitively understand and

respond in respectful and caring ways. Betty speaks about intuition and perception

that inform one's ability to maintain agency in clinical end of life situations in the

following excerpt.

> Betty: I tell nurses that when I go into a room I stand there for a moment and I tell them I kind of just drop everything, and it's almost like you can kind of just feel the emotions. You get a sense of whether there's fear in the room or there's anger or they're scared. I don't know, it's a hard thing to describe but I pretty much pride myself that when I go into rooms the doctor can come out and say oh, they're fine, and I can say oh my, they're not. That patient's afraid of dying and the doctor will say 'dying, they're not going to die.' I beg to differ with you, before I'd even talk to them, and when I come out of the room, there's a whole different story. …I's like they've got a shield across them that they need to drop, and they need to open themselves up to all that is out there and let patients and families in. I don't know how you do that, you've just got to let them do it.

> I: Well it's hard, because also, when you let all that in you're very vulnerable, and you take on a lot of suffering.

> Betty: But how can you ask patients and families to that if you're not willing to do it?

> I: Right.

> Betty: I don't think care providers, nurses and doctors are trained in that art. I think you look, you learn through trial and error. You know when something's not genuine, and when you just scratched the surface level for someone. Part of that is experience, part of that is age, as we talked earlier, part of that again, is knowing yourself.

Agency

Moral agency for the expert nurse according to Benner et al. (2009) is created by clinical grasp, embodied know-how and the ability to see likely future eventualities in clinical situations. "Moral action is tied to the skills of seeing, doing, and being with others in respectful caring ways" (p.157). Benner describes moral agency as associated with providing care that is right and good. Agency requires the nurse's ability to identify relevant moral issues in particular circumstances through perceptual acuity. The skill of embodied know-how with skillful engagement and respectful relationships inclusive of patients, families and co-workers along with timely response are requisites of expert agency. Advanced skills for involvement with patients and families, the ability to manage technology by preventing technological imposition and working with and through the interdisciplinary team to meet patient and family needs encompass the expert domain of agency. The following narrative depicts agency and also highlights spiritual care in congruence with cultural sensitivity. This narrative is related to the care of a teenage girl with end stage gastric cancer in the month preceding her death. She is from Uganda and had only been in the United States for a few years prior to her illness. Betty is working carefully with the entire team to marshal for meeting her spiritual needs.

> Betty: So the physician was so focused on, how are we going to get the insurance to cover her if she leaves the hospital? That's easy, you don't tell them. That's my response, how do they know? So we're not going to tell them. So we went out to the dress stores downtown and asked them if they would loan her a dress. She wanted a really bright red dress, so we brought dresses back for her to try on, the same way with shoes. We had one girl come and do her hair, my beautician came and gave her a manicure and pedicure, we had a photographer come up and do pictures of her. One of the florists

came and made her a corsage and we got her a ride to the prom. It was like an all day event, we had people here all day long doing stuff. It was phenomenal…. We had pictures of her getting her hair done, her toes done. The entire family was here all day long. We were all here, we're checking on her, getting this done and that done. We boosted her with morphine and shut off her tube feeding and disconnected her… I'm giving her the mom talk, 'Now you be home at 1:00. You've got to be back here because you're not going to have any pain meds in you and you've got to worry about this or that'…. We taught her how to do the Miss America wave; she'd walk up and down the hall waving. I swear to God you would never know this girl was sick, she was glowing, beautiful, beautiful…. So a bunch of girls came from the school and went with her… a couple of aides that worked here that were friends with her family all came in and we took pictures galore. Her mom got all dressed up in the Uganda tribal outfit, beautiful, she looked fabulous. So probably two hours of pictures and we walked her down to the car and they left. We all stayed here and waited, and she didn't come home at 1:00 and I was freaking out, because I'm thinking oh my gosh, she's probably in pain or puking. She came back at 3:00 but she was just smiling to beat the band. She didn't think about being ill once. She danced and she said, 'I felt like a normal person'.

I: Wow. And this just happened?

Betty: This was about four years ago. And I remind that doctor, what did it hurt? She went out on a pass, may have had some pain, and this and that, but she was a kid. When that girl grew up in Uganda, her mother's family was massacred in front of her, and her mother had a stroke, and went into post traumatic stress disorder, and this girl at 14 became the mother of the entire family. So her life was never a normal. They moved here, and she was still the mom. So here she was trying to go to school, trying to raise the kids, and take care of her mom, as a fourteen year old and then she got gastric cancer.

I: Gastric cancer, that's pretty rare isn't it?

Betty: It is very rare, but not rare there. So she died at 18 just three weeks after her graduation. You think about what she went through for four years was not normal. For just to have one night to be a teenage girl, and to just experience the senior prom as a normal girl. But it also made the physicians aware, the one thing you don't do in that country, in that culture, is talk about cancer to the patient. You don't talk about dying to Ugandan patients. She knew she was dying, but she didn't want to talk about it… So we did talk, we

talked about life, her goals for life and going to that prom was her goal, and graduating was her goal and that's what she lived to do and once she got that she died…. It didn't matter that she had cancer, that's why I kept telling the doctor, don't talk to her about her cancer, it's not important. What's important is keeping her alive so she can achieve her goals, and that's what our focus was keeping her alive so she can go to that prom. What teenage girl does not look forward to her prom? That was her spiritual side, the music, the dancing, that was for her, the physician would never understand it. But for a young girl that was so important. And a graduation, people didn't graduate in her country, this was huge for her.

Here we have a wonderful example of agency that reveals the skill of involvement, managing technology and working with and through others to marshal for what patients' desire and need. Betty knew by the way of her level of involvement with this young girl her deep desire to attend the prom and graduate from high school. Betty went out of her way to persuade the physician, manage pain and the intrusion of an enteral feeding system. She also enlisted nurse aids and other staff in helping make this young girl's dream a reality. Betty was able to reframe hopelessness with empowerment and create a situation that offered meaning and quality of life while dying. This episode also highlights the uniqueness of the inpatient palliative care nurses ability to make the most of individual's desires for autonomy and control through participatory decision making near end of life. The capacity for agency and attention to spiritual need thus changes the way institutional dying has been traditionally experienced for patients and their families.

Agency has moral, ethical and spiritual elements. It is becoming clearer to me in the context of this research that agency, advocacy and spiritual care are uniquely in a dance together. Is agency a spiritual aspect of care? Is advocacy a spiritual aspect of

care? I believe it is and it is strongly implied in the Benner model of expert nursing

practice. Perhaps the language "spiritual" is left out of the Benner model because it is

so difficult to apprehend through language due to the multiplicity of meaning it holds

for individuals. Definitions of spirituality are broad and do not always neatly fit into

systemized structural models. Yet inpatient palliative care necessitates that we look at

nursing care and agency from a spiritual vantage point. Once symptoms are managed,

existential concerns that add meaning and value to life especially in the context of

death and dying are paramount for meeting patient and family spiritual needs.

Symptom management often involves balancing analgesia so that patients can

participate in events that provide meaning and care of the human spirit. Clinical

aspects of care work in tandem with spiritual concerns to provide agency and the care

patients and their family desire and need.

   As an inpatient palliative nurse consultant Betty is recruited to the welfare of

others. Her role as agent, advocate and spiritual care giver are clear to her. She

describes her work in palliative care as a passion. She cares deeply for people and the

human experience and finds that not all nurses share this kind of passion. Betty

understands spiritual care as taking the time to find out what patients desire and need

and then bringing this into the care environment.

> I: What gives you the passion to do this kind of work?
>
> Betty: There's such a difference when you look at how nurses work, look in
> their eyes, some are just dead in their eyes. Some do their job and they're
> okay, but where's the passion in what you do. If you don't have passion you
> don't care. Seriously, you can do a spirituality assessment in 30 seconds. You
> can ask three questions in thirty seconds, but if you don't even care, who's

going to spend 30 seconds. Then you've got to implement it. When I tell people move that patient over so that the loved one can get in bed with them, and they just look at me like huh? I'm going my God, they're 80, they've never spent a night away from each other, and you're going it's a hospital. This is spirituality here, they need to be together! There's passion.

Connecting with patients and connecting family with their loved one is a passion for Betty which demonstrates agency in nursing care. Agency is fundamentally the summary concept for all preceding domains. The agent as advocate in the sense of acting to voice represents the concerns of another in a palliative situation summing up and integrating all other domains. The hallmark of this evolution of skill and embodiment of confidence comes as a result of experience on both a practical and intuitive level. This is also the notion of craft and artful practice as described in skill acquisition (Heidegger 1927/1962; Dreyfus 1991; & Benner, 1994/2009). When the practitioner has a gap in confidence as regards to their abilities for care, it can denote that the individual is still in an education phase by the way of their own personal embodiment of the aforementioned domains. Now let us turn to a discussion that illuminates the evolution of skill acquisition in spiritual care.

Evolving Expertise

One of the nurses I interviewed was recruited by word of mouth. Her years in palliative nursing were a mix of hospice that occurred over ten years ago and at present in inpatient palliative care in a rural setting. Barb is a 57 year old nurse with 30 years of nursing experience. She holds a Bachelor of Science degree in nursing and is oncology and healing touch certified. She is a seasoned professional and represents clinical expertise in a multiplicity of ways. Yet her interview reveals and

reflects the process she is going through in terms of developing expertise in spiritual

care. A look at the personhood of Barb will assist in understanding her life world and

the concerns she faces with providing spiritual care and how that is unfolding. Her

transcript is illuminating for describing the process one goes through in reaching the

level of spiritual care expertise. I believe this contrast helps to illuminate the nuances

between a proficient and expert spiritual care provider. It also demonstrates the

importance of full agency and how that level of care makes spiritual care possible.

Personhood of Barb

> Barb: My family is German Catholic. I have three sisters and one brother,
> I'm the second oldest, I have one older sister. We went to parochial school for
> twelve years, and I think that the fact of being a Catholic was a pretty big part
> of our identity… as a family and as individuals. I would say it was a pretty
> closed kind of society. Pretty much all of my friends were Catholic, went to
> Catholic school. Our ethnicity is German and a lot of the kids that I knew also
> came from German Catholic families…. I think that one way this really
> affected me was that when I moved away from went to college. I think I really
> had, or still have, the mindset that most people are going to think about things
> the same way I do… that people are going to have the same basic assumptions
> that I do, and I'm still often surprised when that isn't the case….. Everybody I
> knew had pretty similar experiences and thought and felt the same way about
> things. My family was very undemonstrative. I know that my parents loved
> me but they didn't show you that by telling you that they loved you or being
> physically demonstrative in particular. In my family there was a lot of
> emphasis on duty, doing things because you're supposed to do them or
> because that was the right way to do it, kind of thing. I was raised in the
> Catholic Church, which you know, is very dogmatic and by the time I was
> 14… I probably had pretty well decided that I didn't believe most of what
> they taught and kind of gave up on that… and I wouldn't even say that I… I
> don't know if even I believe in God at this point. I'm a Unitarian now… but
> there's really a wide range of belief systems that go to that church. My
> husband was raised in the Methodist church and when we had children we
> became interested in the Unitarian church because we wanted some kind of
> structured framework for our kids, for role models and learning about moral
> behavior and those kinds of things.

I: Yes I am familiar with that church. They have a very inclusive intellectual and spiritual side that I really appreciate. I totally enjoy the way in which Unitarian Universalists celebrate life. You described yourself as dutiful and you feel you got that from your Catholic and perhaps even German background?

Barb: Both

I: Do you think anything else assisted you with being the person you are today and the way in which you care for others?

Barb: Well, just to talk about the duty part of it for a minute. I guess the way that maybe that shaped me now is just in terms of my work ethic, that it's important for me to do a good job and do the best that I can whatever I'm doing.

Barb is a remarkably honest, open and intentionally caring person. Her own transforming understanding of spirituality as greater than religion bound by dogma or congealed absolutes informs her capacity to assist and guide others with openness. She recognizes her parochial upbringing and how that confronts her when dealing with people who are different than herself. Her upbringing also provided her with a value for responsibility, doing things well and a moral work ethic. Barb also expresses doubt, when she says, "I don't know if even I believe in God at this point" she in her own sense is experiencing "a spiritual crisis." Existential theologian and scholar Paul Tillich (1979) informs us in his work on systematic theology that doubt is not a lack of faith but is in reality, just one element of faith. Later dialogue with Barb reflects her "belief in a higher power" and a dimension beyond what we can see, touch and feel. However she is no longer confined by a belief in a retribution theology which defines life in terms Heaven, hell, reward and punishment. Her capacity to confront her feelings, thoughts and beliefs assist her in the genuine care of

others. The following account describes how her life experience and nursing practice

also inform her ability to provide spiritual care.

> I: Did anyone in your family ever pass away; did you deal with death at an early age?
>
> Barb: Somewhat, but I mean grandparents. Both of my grandfathers were dead before I was born. But both of my grandmas died one when I was a young teenager, one a late teenager. I also had several great aunts and older people in the family that died. But these were not unexpected deaths or anything like that. My dad had five brothers, and four of them were Jesuit priests. I always admired them a lot, they've all passed away now, but were really smart men, compassionate and caring, and I admired that a lot in them….But no, I wasn't someone as a little girl who always wanted to be a nurse or wanted to be a caregiver or anything like that. In fact, I can remember my mother commenting to me at one point that she was surprised, of all of her kids that I had gone into nursing… I don't know why, well I guess she didn't think I was a nurturing kind of a person. I guess thinking about things that maybe influenced my journey ending up in palliative care…I guess I would have to say, as a nurse, one thing that I always found as a strength was just being able to communicate with people on whatever level they were at, and the thing I've always loved the most about nursing is kind of helping people to kind of navigate through this whole illness, hospital thing… which is very stressful. It's hard, and it's something that most people don't know anything about, so they need help to find their way through that… and I think a lot of those kinds of issues certainly apply to palliative care as well.
>
> I: While we're on the subject of nursing, did your nursing education prepare you at all to care for a person's spirit?
>
> Barb: Oh no, no, not at all. I don't remember that being addressed at all in any classes.
>
> I: Did you attend seminars or how did you grow into being a palliative care provider?
>
> Barb: Well most of my nursing career has been in oncology nursing, so certainly there is a lot of overlap in palliative care and oncology nursing. I was an oncology certified nurse for a long time, most of my oncology career, so certainly you learn about dealing with those issues, when you're working with

oncology patients. And I guess for myself, the older I've gotten the more I'm interested in spirituality and the idea of spiritual issues… maybe 20 years ago I would've said no, that's not important at all and now I would say it is very important for most people and for myself included. I think I've just broadened by idea of what spirituality really means. I do plan to get certified in palliative care.

I: So what is your broad idea, while we're on that topic?

Barb: Well to me something that encourages spiritual growth is something that kind of encourages you to be connected with something larger than yourself, something outside of yourself, and also something that is nurturing and enriching for you. For a lot of people that is the idea of God, and being part of a religion and prayer and those kinds of things, and that isn't really so important for me. But I really do kind of, in my own life, try and seek out things that nurture my spirit and help me to, I don't know what, be more open… if that makes sense, and so for me it seems like, music, playing music, singing, listening to music, being outdoors, gardening, doing things in the natural world.

 I: So nursing education really didn't assist you, your understandings are pretty personally and experientially derived. Any other life experiences that you think contributed to your ability to provide this kind of care?

Barb: Well yeah, I would have to say my experiences with death in my own family and in my husband's family over the last few years. His mom passed away several years ago, my dad died. His dad died actually two weeks ago after a long history of dementia and really a slow decline. My own mom is still living but kind of starting to go through the same thing, kind of slowly progressive dementia…it just makes me think about what's meaningful about life. I mean as I look at my mom who's just kind of losing interest in things in general and has always been a pretty closed person… not really open to new things, and of course she's more that way now that she's 87 than when she was younger…. Yeah, it just makes me think well what gives your life value, what makes your life meaningful, and after you're gone is it even going to matter that you were here. So I think that's somewhat what drives me is thinking about those kinds of issues.

I: So do you think when you care for people that you try and facilitate meaning for them when they are faced with end of life?

> Barb: Yeah, yeah and I think something really simple like just encouraging some life review with them and also with their families to just… I don't know give it some perspective to think about what is the meaning of all this. I think it's helpful for people to kind of process those kinds of things.

Barb's own life review and acknowledgement of being a help and guide for vulnerable suffering people, as well as the desire for meaning making assists her in engaging the spiritual aspects of her practice. Her grounding in a moral work ethic and "doing things right" also inform and challenges her understanding of nursing and how that fits with attending to the human spirit in the context of her role. Objective clinical findings and quantitative rules and maxims no longer fit or assist with her evolving role in spiritual caring. The following discussion is related to describing the transforming evolution of proficiency toward expertise.

Proficiency

The evolution of expertise involves a transition between the proficient and expert level of practice. Benner et al. (2009) describes proficiency as a transition to expertise.

> Proficient practitioners can read a situation, recognize changing relevance and accordingly, shift their perspectives on the whole situation. It is the ability to read the situation instead of laying on a preconceived set of expectations that makes expert practice possible. However, for the proficient nurse, ways of responding are not yet linked to ways of seeing the situation, so the nurse at the proficient level still has to think about what to do (p.137).

Improved perceptual acuity and learning differentiated responses are characteristic of this stage. It is also important to note that experience in terms of time may be helpful for the nurse in transition but experience cannot be understood by the passage of time alone. Otherwise one would expect expertise from Barb in all aspects of care, given

her years in nursing. Gadamer (1975) explains experience beyond the confines of

passing and relates this in terms of active transformation and sophistication of

expectations and perceptions in evolving situations. As Barb confronts clients with

varying illness trajectories and individualized spiritual needs at end of life she must

reason her responses through time and evolving situations. This also fits the form of

being described by Heidegger (1927/1962) as "unready-to-hand" and involves

conscious deliberation before response. The following expert from Barb illuminates

her evolving practice and the challenges she faces when attending to spiritual care

needs of clients.

> Barb: Well let me say that I really never thought of myself as a spiritual care
> provider. A lot of the time I still sort of feel like, I don't want to say I don't
> know what I'm doing but, it's not directing things… it's just me trying to
> open the door and then the patient and the family are going to take it where
> it's going to go. Plus, just the whole idea as a nurse… most nursing jobs are
> pretty task oriented. For the two years before I was doing this my job had a
> clear agenda. When you go to see a patient, you know what your role is, you
> know what your agenda is and it's real goal driven and it's easy in that way.
> Because it's kind of like everybody knows what you're there for and what
> you're trying to accomplish. It's been difficult for me, palliative care isn't like
> that, it isn't like that at all, and you don't know what the goal is going to be
> always… Sometimes, if the patient is in pain, you've got to get them
> comfortable, that's clear cut. But a lot of times you don't know what that
> patient's agenda is or where it's going to go… and so the idea that you can't
> push it, you have to just be there and let whatever's going to happen, happen.

This narrative describes Barb as operating in the quintessential proficient level of

practice. She describes the difference of having a clear cut agenda in former nursing

roles and the challenge of moving into a vague, grey area of spiritual care in palliative

care. Her perceptual acuity is evolving as she realizes there is no clear cut prescriptive

way to engage her clients. She sees the concept of her "agenda" as now shaped by the

demands of varying and particular patient and family situations (Benner, et al. 2009).

Spiritual care involves being attuned to the needs of others and connecting in ways

that are comforting and helpful.

   Betty in contrast to Barb, and reflecting of expertise in practice, made no mention

in her interviews of conflict with her own or client agendas. She has a full awareness

of individual transcendent meanings and concerns and fluidly is able to assess and

implement care while connecting with others without deliberation. Conversely, nurses

functioning at the proficient level must learn enriched and discriminating skills of

emotional attunement and involvement. Confidence with this is further complicated

by the diversity and difference in patient and family needs, comfort levels and

expectations as depicted in this excerpt from Barb.

> Barb: I think the biggest challenge for me, it well it doesn't necessarily have
> to do with spiritual care, maybe it does have to do with spiritual care more
> than other aspects of the role… it's just, I don't know, feeling like I can do it.
> Feeling self confident that I can do it, and we talked about this a little bit
> before, that there's this process of development when you start out in the
> role….But a lot of times I'm apprehensive about going into a room, maybe
> it's somebody that I haven't met before or I don't really know them very well,
> I don't really have a connection with them yet… I find myself kind of
> anticipating how is the conversation going to go. Well if I say this, then they
> might say that. Well that's silly because I don't know what the heck they're
> going to say, I don't know what direction it's going to go in, and probably,
> whatever they say I'm probably not going to respond in a way that's too
> horrible…. You know what I mean, I'm not going to stick my foot in my
> mouth, but that's a pretty big barrier for me. Again, I think, to me one of the
> big challenges of being a palliative care nurse is just kind of that you have to
> learn, you have to know a lot about yourself and what prevents you from
> being able to respond in a real open way…. I think also, if you don't have a
> lot of self confidence in the role you hesitate. I mean sometimes I think it is
> appropriate to push a little bit with patients or families to try to get more

information, and sometimes you shouldn't do that. Sometimes if you push you're going to alienate them. I don't always feel like I'm skilled enough at kind of picking up cues to really know what's going to be the best thing to say to help make a connection with the patient or encourage them to express whatever it is they want to express.

Barb is describing her struggle with the advancing skill of emotional attunement. Her practice in palliative care has not yet offered her enough or perhaps too much diverse experience with spiritual caring situations to give her a strong perceptual grasp. Comparatively Betty's language did not reflect uneasiness, she spoke confidently about knowing herself and her ability to connect was evident. The uneasiness and emotional language depicted in this narrative from Barb is characteristic of an experiential learning stage. Evolving emotional attunement is characteristic of the proficient level of practice and assists the nurse in doing what needs to be done. Benner et al. (2009) states,

> To have a perceptual grasp of the situation is to have an emotional tone related to the situation. Emotional responsiveness and tone are central to having an embodied skilled know-how and signal an understanding of the situation as well as a way of being in it (p.108).

The following excerpt reflects the frustration and coping while situated in the "unready-to-hand" form of being when providing spiritual care.

> Barb: That's hard, because then, if nothing happens, sometimes you don't make a great connection. I feel like oh, I must be doing something wrong, I should've said something different or I should've asked just the right question that would make them open up and spill their guts right? And just to accept that that isn't always going to happen, and if it doesn't happen it's not because I'm doing something wrong, it's not because I'm not doing something that I should do. That's been pretty hard for me, and that continues to be hard, although it's getting easier the longer I do it. But it's a challenge for me because I think some people are good talkers, they're just good at visiting with

people. I'm not particularly good at that, so yeah, I feel like I should be able to do something to make that person want to open up and talk to me.

Barb uses the word should four times in this short excerpt. She recognizes the challenges of her role and resorts to moralization. This also highlights how the developing the skill of involvement is linked to moral agency and ethical comportment. Her sense of what she "should do" is clearly a conflict for her. Barb in her frustration resorts to naming the skill of involvement as visiting which indicates rationalization and coping with the challenges set before her. She is in the process of refining the skill of emotional attunement which once learned enriches involvement and sets up the possibility for embodied know-how, full agency and expertise in practice. Or as Heidegger (1927/1962) would name it "ready-to hand" form of being. Comparatively, Betty's intuitive skill and embodied know-how was evident. Betty spoke about how she is able to read a situation through tone and mood that often physicians often ignore and is probably related to less sophisticated levels of emotional attunement and involvement. Spiritual care in the inpatient palliative care setting requires the nurse to have a clinical grasp of the situation by virtue of their past practical knowledge while simultaneously fused with perceptual acuity. This fusion permits intuitive skill and is the key difference between a proficient and expert level of practice. Barb's ability to know the difference at this point in her practice adds to her doubt as depicted in this account.

> Barb: I think there are people who are really intuitive and really are able to
> easily make a connection with other people or are kind of able kind of intuit
> what would be helpful, what would be comforting to that person…I'm not that
> way. I mean I am not, I'm much more the type of person you think about
> something and you figure out how to do it...then you practice doing it, and this

role makes it challenging. But on the other hand, now this is really hard for me, I'm going to cry… because it's something that I really struggle with…. On the other hand, my professional colleagues always tell me, 'oh you're perfect for this role, you're so great in this role, you're such a good listener, and you're so easy to talk to.' I don't think of myself that way at all…. But lately I've been thinking well shoot, if other people see that, and if that's what other people think about me, then why can't I be that person?

I: I think you are. Maybe you just didn't hear it a lot. And you have offered so many insightful thoughts and understandings today.

Barb: Well thank you and No, I never heard it, that's for sure. So anyway, yeah, this is definitely a real growth experience for me. So yeah, that's what I've been telling myself…. I was talking to our volunteers in our program and they say 'Oh Barb, you're so supportive of us, you're so great, and you're so helpful.' I'm thinking well damn, okay. So maybe I am that person and I just don't know it.

I: Working in palliative care is huge in a transformative way for one's own psycho-social and spiritual growth and development.

Barb: Yeah, I think so too. And just the whole idea, I think people in general need to have a broader understanding of spiritual care and what that means because there are a lot of different dimensions to it and it's not just talking about church or religion necessarily. And everybody has spiritual needs, even if they don't think they do.

I completely sympathized with Barb and her evolving role. Moving into a specialty of nursing that requires tacit skill verse objective fixing of problems is fraught with ambiguity and frustration. We both resonated with concepts of coping occurring in this phase of skill acquisition that included avoidance, resistance and fear. We also shared an understanding and uniqueness about palliative care at end of life where the patient, family and nurse all share an ambiguous experience albeit with obvious distinctions.

I tried to assist Barb as she described her doubt and frustration with emergence from an embedded world of nursing absolutes. I told her that I myself watched and modeled many people including other palliative care nurses, chaplains, physicians and staff nurses who possessed the tacit comforting skills I wanted and needed. I told her that I viewed my own spiritual care development like a DNA molecule which unravels off its helix, transcribes and transcripts information with the threat of coming completely apart at many stages along the way. However it is in this process, that the organism is perpetuated and each living organism is unique. This is true in cellular evolution as well as in the evolution and acquisition of skill. I affirmed how I was certain she will uniquely transform and come in to her own as a spiritual care provider. What is remarkable to me is by the second interview, just four weeks from the first, Barb was able to articulate increased levels of spiritual care expertise. Benner would agree that it is in this time of proficient practice that dialogue and support are vital for engendering expertise. I find it profound that spiritual care involves dialogue, support and assistance with meaning making for helping patients and families make the qualitative leap between life and death, despair and hope. Dialogue, support and meaning making also very much assist the proficient care giver with their own transforming role toward expertise. The following narrative reveals Barbs emerging expertise in spiritual caring.

> Barb: I'm thinking of one patient with acute leukemia, and initially when I first met her, she's a very nice, very friendly lady but pretty much told me initially thanks for stopping by but I'm really doing fine and my family is here every day with me and I have lots of support. So there isn't really anything that I need from you right now, kind of a, don't call us, we'll call you kind of feeling…. So I didn't push it, because that's really counterproductive. I

continued to stop in and see her… and kind of hi, how are you doing, and keep it light. I guess it feels like a success story to me because over time I think what happened is the patient started to trust me more than she did initially and began to use me as a source of support…. This is somebody who, maybe matriarch's too strong of a word, but she is kind of the matriarch of her family, she's kind of the person in charge. She's the person that takes care of everybody else in her family. So yesterday when I went to visit her I just felt like she was able to kind of let that guard down a little bit more and she was kind of teary and cried off and on during the conversation. She talked about how she's probably going to be discharged maybe tomorrow, real soon, and she had some problems with cardiac function while she was here so it's not clear whether she's going to be able to get any more chemo because her heart function isn't good enough now… So she cried and was just able to talk about the fact that she's scared about going home and talked about her fears, and I think that it helped her to be able to do that… to cry and just be able to let that out a little bit and talk about it, talk about possibly dying, and her desire to take care of her kids and her other family members and so on…. She's been here more than a month and that was really the first time that she really, even though we've had some nice conversations, that was the first time that she had really opened up in that way. So I felt that it was a positive thing for her, and I think the thing that it made the difference that I continued to be there. I don't know that I did anything different other than I just kept showing up and we'd talk about whatever she wanted to talk about and that trust kind of developed over time.

I: Perhaps your abiding presence and persistence, in the end broke the barriers, she felt she was self sufficient and she had enough support, but ultimately she really did reveal her vulnerability to you.

Barb: Yeah, I think so.

I: And she needed to lean on you. With her role, being the matriarch, how often do those people get to lean on other people?

Barb: Not very often.

I: How do you know the fine line between when you're annoying someone and when it's okay to push ahead with that presence or persistence, what do you think tells you that?

Barb: Well I think a lot of times its nonverbal cues. I mean I've had the experience of walking into the room and just that initial, right away reaction

that you get from a patient, you can see it on their face, that they're thinking 'oh crap, I was wanting some down time here or whatever and now here's somebody else here to bug me', and you can see that. It's probably only going to be there for a second and then they're going to cover it up because people are nice, and most of the time that's what they do, but you see that, if it's there. Mostly I didn't see that with her, maybe more a little bit initially…. Then too, the longer that she had been here in the hospital, she didn't have quite as many visitors as she had initially because they're from M, that's 60 miles away, so yeah, there wasn't always a family member there at the bedside. So as time went on, I think the nonverbal cues that I would get from her when I would come in the room were more like 'oh great, it's you' kind of feeling. So that tells you oh, okay, I am wanted here so I'm going to keep coming back even if it's just to say hi, how are you doing? I just wanted to let you know I'm thinking about you.

Barb reveals an awareness of the importance of developing trust and providing presence in spiritual care. This evolving self realization includes engaged reasoning as evidenced by Barbs ability to discern changing clinical conditions and concerns such as her patient's cardiac complication and ability to pursue chemotherapy merging with the spiritual needs heightening along with the uncertainty of this illness. Barb is more skillfully emotionally attuned to the situation and does what needs to be done by being relaxed and persistently showing up to see the patient. She no longer deliberates about what to say, nor do, her intuitive sensibilities have emerged along with her self confidence. She is able to recognize changing relevance, both in terms of the clinical changing course of events as well as the social change of events with a family who is unable to be with her for this extended hospitalization and its changing relevance for spiritual needs. This awareness of changing relevance assists Barb with a more skilled sense of agency and enhanced level of involvement. Barb is transitioning nicely to expertise in spiritual care practice.

The Existential Art of Expert Practice

The beginning of this chapter attempted to engage an understanding about the successful cultivation of a craft. The acting profession as well as nursing historically has not relied on theory or empirical methodologies to undergird practice. Both of these professions did not begin to formally theorize until the mid twentieth century. None of the nurses I interviewed for this research had formal theoretical training on spiritual care. Experiential learning and the associated practice of practical skill unite with increasing perceptual acuity and intuition to undergird expertise in spiritual care (See Illustration 1). Hubert and Stuart Dreyfus in Benner's text *Expertise in Nursing Practice* help us to understand the relationship of theory and practice in the acquisition of skill through a brief historical reconstruction of Western philosophy.

Practical Skill   **Perceptual Acuity**   **Intuitive Understanding**

Illustration 1   **Expert Spiritual Care**
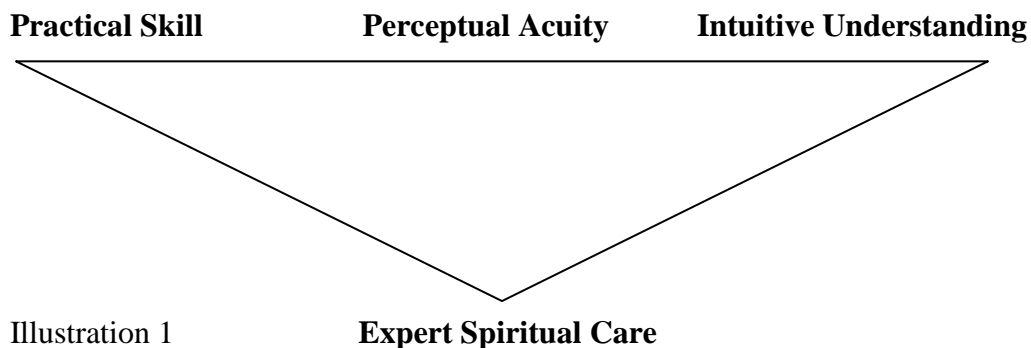
The Dreyfus brothers suggest an evolution of thought regarding expert skill as synonymous with craft wrought out of Western philosophy beginning with Socrates, evolving through the Platonic rationalist tradition and culminating with Aristotle's view of expert craftsman. As stated, "In his book *Physics,* Aristotle states 'Art (*techne*) does not deliberate.' Moreover, Aristotle was clear that even if there were universal principles based on theory, intuitive skill was needed to see how the

principles applied in each particular case" (p.5). This is where Heidegger in the twentieth century picks up on the ontological forms of "Being" and explicates the readiness to hand mode as one in which intuitive understanding is fused with responsive action and such phenomena as mattering, possibilities and inhabiting a shared world are grounded by existential accounts of human being.

Aristotle also delineated concepts of *praxis* and *phronesis* and these concepts have been contemporized and are reflected in the definition of practice by the philosopher, Alasdair MacIntyre (1981) who stated,

> A practice is any coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conception of the ends and goods involved, are systematically extended (p. 175).

Here we have a definition of practice that includes phronesis or "mindset" and custom of practical wisdom and prudence alongside praxis, which is the purposeful reflective ethical action that occurs through an engaged social context. Both of these concepts involve intentional ethical human conduct (Benner, 1994/2009; Dunne, 1997; Gadamer, 1975; Kesselring et al. 2010). Benner's concept of expert and the associated domains of clinical response based practice, embodied know-how, seeing the big picture, seeing the unexpected and agency combine the philosophical notions of techne, phronesis and praxis together that are fused and existentially reveal expertise in nursing.

Nursing practice involves the practice of multiple practices including science, art, sound judgment and ethical action. This chapter and research study illuminates the practice of spiritual care expertise at end of life in an inpatient palliative care setting. Dr. Patricia Benner, an accomplished scholar and teacher of philosophy and nursing has translated, synthesized, and imparted knowledge from of the philosophical and phenomenological sciences for nursing that otherwise may have eluded our profession. In doing so, she uncovers the very essence of caring and the "Being" of nursing as a healing art. Her work greatly assisted with my examination of how spiritual care fits the expert model and is meaningful in the context of inpatient end of life care.

Summary

The interpretive narratives of two inpatient palliative care nurses presented in this chapter represented a paradigm case of expertise and exemplars of the proficient level of practice evolving toward expertise. Betty and Barb both represent being in the world of inpatient palliative care at end of life where spiritual care matters. Their ability to respond successfully to meet patient and family spiritual care needs demonstrates tacit skill and the craft of nursing practice that manifests spiritual care and provides holistic quality end of life care. These narratives illuminate the convergence of craft oriented practical skill and growing perceptual acuity fused with intuitive ways of knowing and responding, moving tentatively at the outset but eventually inexorably toward unification and manifestation of expert spiritual care. We now investigate further how individual practitioners move a step closer to the self

realization of expertise in spiritual care through the notion of the humbled expert and

its associated sub themes.

Chapter Five: Humbled Experts

Lord, make me an instrument of your peace.
Where there is hatred, let me sow love;
where there is injury, pardon;
where there is doubt, faith;
where there is despair, hope;
where there is darkness, light;
and where there is sadness, joy.

O Divine Master, grant that I may not so much seek
to be consoled as to console;
to be understood as to understand;
to be loved as to love.
For it is in giving that we receive;
it is in pardoning that we are pardoned;
and it is in dying that we are born to eternal life. Amen

Saint Francis of Assisi

Introduction

Saint Francis of Assisi, medieval, mystic and monastic composed this famous

prayer of poetic paradox (Tyson, 1999). The word paradox literally means, "a

statement or proposition seemingly self contradictory or absurd and yet explicable as

expressing a truth" (Webster, 1975 p.1075). I have chosen a theme of humbled

experts to collectively represent the personhood and spiritual care practice of the

palliative care nurse consultants I interviewed for this study. I choose this theme

because it is paradoxical. Our human understanding of expertise in the professional

health care community, including the empirical and the rational is often in

contradiction with humility. Yet in the context of spiritual care at end of life, nursing

expertise is predicated on being humble and humility is of the essence for providing

care and comfort. This chapter includes all the voices of the participants in this study

as fitting within the humbled expert theme. A discussion of subthemes including

relational stance, enlisting other experts and new found concepts regarding the ABC's

of spiritual care are also presented and assist with highlighting embodied features of the humbled expert. Prior to discussing the subthemes the chorus of voices that emerged in this study is presented.

The Chorus of Humbled Experts

The participants in this study represent a mature demographic of nurses who have become experts in the field of nursing, particularly end of life care and are actively employed as inpatient palliative nurse consultants. Generally speaking these nurses represent a similar social group in terms of age, years in nursing, socioeconomic class; religious background and participation in faith tradition.Ten females with a median age of 54.5 years in life, 31 median years in nursing and 6.5 median years of palliative care experience are featured in this study. All of the nurses reported active participation in a faith tradition, nine are Christian and one is a Unitarian Universalist.

These nurses all embody a humbled expert stance relationally with the clients they serve. Additionally everyone in this study recognized how it feels to be slighted and have experienced loss, some through personal illness and many through family illness and death. Not one of these participants had any formal education regarding spiritual care at end of life within the context of their original nursing education. What little knowledge they did receive, was just the tip of the iceberg. Bev when asked if she had received any training on spiritual care in nursing school said, "No absolutely not, oh wait I take that back, we had a lecture on the five stages of grief, one lecture, that was it." Melissa sees spiritual care as part of the holistic model of caring in all settings and said, "Nurses provide spiritual care all the time, but not formalized like a chaplain

would, but they do and sometimes we don't even realize that were doing it. It's part

of our overall nursing care that isn't defined as spiritual but it is." All of these

participants had additional continuing education through conferences or personal

study. Yet it was largely through their personal life experience and evolving expert

nursing practice that they learned how to recognize and offer an alternative to

spiritual suffering.

    The following excerpts represent multiple voices in this study that reinforce the

notion of humbled experts. The opportunity to provide care at end of life is described

as a "gift" and the role of providing presence, support and spiritual advocacy is

described as one of "honor and privilege". The capacity to provide this kind of care is

often related to the nurses own experience of suffering and loss, growing spiritual

awareness and learned ability not to judge others. The experience of being with

people undergoing loss and death creates a context of hospitality, invitation, and

mutuality of care; these experiences have enlarged the nurses own perspective on life.

Listen carefully to the chorus of humbled expert voices that emerged as I inquired

about the nurses own life and practice.

> Jane: I was going to see another patient but physically felt like I was drawn
> to go instead to see her. As I got there she took her last breaths and her
> husband was there. I took that as a gift that I was able to be present with the
> husband and we just stood there and we held each other and cried. It just felt
> like it was a beautiful time. We had this ongoing relationship, there were
> many things that were discussed and decided upon, she was pain free, and her
> death was very peaceful. People very much invite you into their lives; I take it
> as an honor to be part of that.

> Melissa: So I went I went to the room and the patient had just died and I
> stayed with the daughter and she was screaming on the floor, so I got on the

floor with her and tried to support her. I spent a lot of time with her, not always saying anything, just being present with her, holding her hand. Most of the time I try to ask if I can touch or hold their hand, sometimes I just give them a hug, and you can tell if a person's going to accept that or not. If I didn't think that was the appropriate thing to do then I wouldn't. But one of the physicians said to me, that's not your job... I'm thinking it is my job, that's part of palliative care, to support the family, that's really what the nurse does, you know, and it is partly spiritual, if I feel like they need more assistance, I often call the chaplain but I'll also pray with them myself.

Sophia: Being older and maturity helps, I think, to try and hold it together. When someone dies and the patient's family is crying, emotionally I can hold it together. I think I have enough awareness that I don't try to say something because often there is nothing to say, and the best thing I learned early in nursing, is presence. I can sit down and hold a hand or just pat somebody on a shoulder and just being there is the best thing I could offer at times.

Vicki: I have learned not to be judgmental of people and to accept people for who they are. Before this, I took care of patients in their homes in this community, we're a poor community and we see very poor people with nothing, dirty homes, very sad situations, high illiteracy rates, and we have a high incidence of cancer in this area too. I had such limited exposure early in my nursing career, it just didn't seem like there was so much emotional pain and suffering... Gosh, when you started talking to some people, ones who had been raped as children by their fathers or they had grown up with so many tragic events, I wasn't even aware of that… I was really sheltered. It was also working in hospice and palliative care that was eye opening for me, because you go home humbled every day from that. You think I'm so grateful for what I have, I'm so grateful for my family.

Lucy: Well I think going back to the home care and hospice piece. All that experience I think, it was real privilege to be able to go into their homes and really take in the dynamics of how they interacted as a family and how they dealt with crisis and grief and various things… I think that probably more than anything it's made me realize that you can't be judgmental, that everyone is very different and there isn't a right way and a wrong way, it's just their way. I think that it's made me more open minded to the fact that every single family is different. I truly think that the biggest piece is sort of trying to put yourself in their shoes. As impossible as that is completely to do, but trying to put yourself in their shoes and saying to yourself, if this was me and I were in this situation, what would I want to hear?

Invitation, hospitality, support, presence, non judgment and the recognition of gift and grace represent the manners these nurses embody while providing spiritual care. Benner, (1994/2009) calls this "ethical comportment," an attribute of agency in expert nursing practice. It is through the manners and humbled relational stances these nurses take, that engage and permit actualization of spiritual and transcendent meanings and concerns. It is through the practice of ordinary acts of responsibility that clients perhaps experience in their last moments on this earth the very mystery of our existence. Religious parlance would speak of this as participation with an "experience of the redemptive activity of the Mystery at the heart of things" (Dykstra, 1999). The nurses in this study all represent participation with a faith community and many testified with conviction a reinforcement of their spirituality, mutuality of care, and mystery of human existence they experience while attending to the spiritual needs of others. Cindy has direct personal and professional experience with loss and the redemptive nature of spiritual care inclusive of God, self, and others. She highlights the void that exits when spiritual concerns are dismissed and death is denied.

> I: Well you talked about your grandmother committing suicide when you were a teen, and in your parents' efforts to protect you, you felt excluded.

> Cindy: I was probably 12-13 at the time… We weren't told a whole lot. Of course at that age your ears are big and you overhear things, and I knew what had happened and I mourned. But we weren't allowed to go to the funeral or participate in any of that… It was a negative experience as far as that goes. I always felt bad because I wasn't allowed to be part of that and I wished I had been… I just clearly remember that time in my life when that bad thing happened and we were excluded…My grandmother had been a nurse and I think that influenced me as far as my choosing to become a nurse.

I: Did anyone else in your immediate family die when you were younger, or have you had any friends pass away?

Cindy: Later in life but I have, though in my mid adult life… I'm a cancer survivor myself, I have had a brother in law who died of cancer, and my mom died of cancer, an uncle died of cancer. We've had a lot of cancer in our family, so I've experienced a lot of death as an adult in our family.

I: So do you think that has influenced you in terms of you being a palliative care provider?

Cindy: Oh definitely. I think that's why I initially was asked to participate in putting our team together here at the hospital. People knew my experiences, my cancer, my mom's happened at the same time, we had the same kind of cancer, she died but I lived. Then my brother in law died six weeks after my mom, and people knew all of this since we're a small community. So that's kind of why I got pulled into this, they thought I'd be good at it, and my past experiences have helped a bunch.

I: How would you say it's helped?

Cindy: Well, I've had surgery, chemotherapy, radiation. I understand those things, I understand the side effects, understand the feelings and the anxieties and the fears. I think that just helps me relate to the patients and the families pretty well. My illness also strengthened my faith, and certainly because I had a lot of prayer at that time, I was baptized at that time. So I think I kind of went through a transformation during my cancer treatment that increased my faith and strengthened it.

I: So you rely on your religious beliefs and the rituals that you've learned as a Christian?

Cindy: I think for self support as well as trying to help support others. Certainly I think faith is really, really important. It's important to help get you through crisis, and no matter what the outcome is you need that.

I: Okay. Any other ways that maybe are not traditionally religious that you feel give you hope?

Cindy: Oh I think I'm just very family oriented and just, I've got two teenage boys and as I see them grow… those things give me hope and strength. So I think family is the next very important thing, and I see that with the people I

take care of all the time. The one's who have family and loved ones that are concerned… it's just a better experience all the way around.

Cindy's dialogue highlights the intersecting relationship inclusive of God, self and others that is well articulated in the spiritual care literature. Her short dialogue bears attention to this intersection and highlights the things that matter to her in terms of spiritual care and practice. Dunne, (1997) discusses how practices rely on socially embedded practical knowledge and both shared and tacit background meanings enter into the world of nursing practice in this setting and others. Cindy's experiences of being excluded from her grandmother's funeral, personal illness and multiple losses of loved ones combine to inform her nursing practice. Her "Being" represents as Gadamer (1975) described a "fusion of horizons" with those she cares for. This put simply is a shared social reality or understanding of and participation with others who face similar exclusion, dislocation, illness, fear, anxiety, and death. Cindy's very "Being" and capacity to respond to suffering is grounded by her personal and professional experience. This "fusion" is affirmed by those who knew her well and professionally recruited her to start the palliative care program. They in their wisdom knew that given her lived experiences, Cindy would be a tremendous asset and help in this setting. The following excerpt from Donna summarizes the honor and mystery of life revealed to her while providing care.

> Donna: I don't know how to say it. To me it is really an honor to be able to assist people on this journey, this really important time of their life, and everybody's needs are different. I'm trying to be flexible in being able to focus on what does this person need from me right now, what can I do for them, whether it's physical, emotional, or spiritual, all of the above…. It is probably part of the, I guess expertise of palliative care, meeting that person's

needs whatever those needs are and being able to be flexible enough to hop around a lot. I don't know if that makes sense.

I: No, it makes a lot of sense, and it's important to say that, that it is an honor and privileged role, not everybody even gets the opportunity to take that journey.

Donna: People are very honest at the end of their life and you get a glimpse to see into their soul. I've just seen some amazing things, amazing people that I never would've guessed had the depth that they do. It really reaffirms my spirituality because I see souls, I see spirits, they're incredible beings, and I know they're going to go on. It never ceases to amaze me, creation, life, death, rebirth and the whole ball of wax. So it reaffirms my spiritual beliefs too, I get a lot out of it.

I: That's great. Seeing and being with people especially at end of life how does this change your perspective on things?

Donna: I would say the power of the human spirit has amazed me and humbled me a lot. I feel very fortunate, and it puts the rest of my life into perspective too. Other things are not a crisis to me. They may be a hassle but not a crisis.

The chorus of voices reveals that through a humbled relational stance the client and family experience, support, presence, non-judgment, and empathy. The nurses describe the opportunity to provide spiritual care as one of "gift, privilege and honor." The following discussion further illuminates the relational stance these nurses take when providing end of life care.

I and Thou Relational Stance

Experiential learning throughout the years engendered responsiveness from these nurses when dealing with people undergoing, tragedy, loss and fear of the unknown the courage and empathy to provide for their clients what metaphorically I call "bread instead of crumbs." They accomplish this largely through a relational stance they

maintain with their clients which Martin Buber, (1958) named an "I and Thou"

relationship. This relationship is a subject to subject verse subject to object way of

relating and necessitates a humbling of self and reverence to another for full

engagement. Pohlman (2009) discussed critical social theory and the work of

Foucault. In her research she discussed the technological gaze that persons fall victim

to in the health care setting and the objectifying stance this creates in modern

institutional care. The nurses in this study intentionally work to create and embody a

subject to subject stance. Within this relational stance the participants of this study

describe feelings of mutuality, hospitality, privilege and honor. The following

excerpts illuminate some of the personal understandings and professional experiences

that engender and illuminate this stance.

> Bev: I have a little thing I have above my desk that says if you do what you truly enjoy you'll never work a day in your life, and that's exactly what I feel I do…. I was with a man today that we're sending home on hospice tomorrow. I've been fortunate enough to know him for 2-1/2 years because I helped him with his wife when she died. He and his six children are just wonderful, and I thanked him when I left him today for allowing me to care for his wife and him. I told him it was a pure honor to be able to do that, and it is. It's walking a path with people that have invited you into their lives. To be able to help people at this time of life, their most difficult, to take that last step with them is truly an honor.
>
> I: In 35 years of nursing, how would you say your spiritual awareness and your capacity to meet these needs for others evolved?
>
> Bev: Oh that's just maturity; I think it's more obvious because I'm in the nursing field and what we see every day. I'm so thankful, there but for the grace of God go I, you know, we've got that perspective as a nurse, but beyond that I think it's just becoming older, and as you become older I think your spirituality develops more, because you recognize the meaning of life and the fragility of life, the like I said, there but for the grace of God go I.

Bev describes herself as cradle Catholic. She holds firm to her belief and faith conviction that as she stated "I was born to love and serve God and others." She has a seminary education with a Master of Arts in health care mission. She has 35 years of nursing experience and shared a positive personal experience during her father's death that influenced her own professional decision making and career path. Her father was in his seventies when he entered hospice and been given a prognosis of anytime, yet he lived for another twenty months. Bev after witnessing the care and connection made between hospice staff and her father, decided to leave her position as department head of managing an entire operating room staff to developing an inpatient palliative care program. She said she valued her management role and all she had learned but also said "I was tired of managing people" she desired to move into a professional area where she could connect more with others. She considers this an honor and privilege. In later dialogues she highlighted how personal experience with loss in addition to providing insight and help for others also has the potential for interfering with spiritual caring. This occurs especially when personal self disclosure supersedes the awareness of client needs. Bev is clear about the importance of humility and this assists her in maintaining an "I and thou" or humbled relational stance.

> Bev: I see this at times when not so much patients, but families are struggling to do the right thing for their loved one. Someone on the health care team when we're having these meetings will all of a sudden start talking about something in their personal life, something in their own family involving a crisis…. I think they do this thinking that is going to help the family from a spiritual standpoint with their decisions. It doesn't, and that is a struggle for me sometimes because, it's irrelevant. If the family wants to know more they will ask you about your personal life, but for the most part families don't….Later families will say to me oh, I felt so sorry for him (referring to a

health care team member and personal story of loss and difficult decision making) and I'm thinking wait a minute, it's not a about him, it's about you.

Self disclosure regarding personal experience and or beliefs can be beneficial and may enhance the involvement of care. But central to spiritual care is a client centered therapeutic relationship. The caregiver must continue to examine if their motivation for self disclosure is meeting their own needs or the needs of their clients. Taylor (2002) when discussing spiritual self awareness suggests the nurse ask themselves, "What is the purpose of my self revelation? For whom is this disclosure? Will my disclosure enhance the therapeutic relationship?" (p71). This holds true for the disclosure of personal life experience as well as personal beliefs and values. Bev views her relationship with clients as "invitation" and responds to their hospitality to co-journey with them at the most difficult moments in their life as one of "honor and privilege." She is very aware of the difference between self serving commentary and communication that meets the needs of others. Through this awareness she is able to embody a humbled expert relational stance and that includes her ability to enlist other experts.

Enlisting other Experts

Bev's humility assists her in careful discernment of her nursing role as well as the expertise of the entire palliative team. She views spiritual care as inclusive of all that gives meaning and value to life including the religious aspect of culture that for many apprehend and articulate the essence of spirituality. She considers the focus of palliative care one in which you utilize the entire team to holistically meet client

needs. This team approach highlights her expert agency and ability to work in and

through others to meet client needs.

> Bev: I always, well I won't say 100% of the time but for the most part I have the chaplains come in and discern spiritual needs. They are the experts in that field; they are more equipped to respond to patients from an active religious standpoint as well as general support and spiritual guidance… I also make sure that patient and families are connected with their community clerical leadership if this is something they desire. I know I am out of my realm when it comes to specific religions so I always ask the experts… Enlisting all the experts in the care of patients is really what palliative care is all about.

Every nurse in this study spoke to the value of their pastoral care departments for

meeting spiritual care needs. Many reported a strong working team relationship with

pastoral care. Sophia a nurse practitioner in this study highlighted the importance of

chaplain service and the team approach of meeting spiritual care needs.

> Sophia: We have a chaplain for our team and then we have access to 24 chaplains throughout the hospital here. I work very closely with chaplains because so many times people are coming in, receiving bad news, and they need the support that medication can't give. I just had a family meeting today and the chaplain had talked to the relatives the day before and established a relationship. Spiritually they were in acceptance that this was a life limiting illness….Now the question was how can we bring comfort to the patient? So every time I have a family meeting, if there is an established faith or an established relationship with the chaplain I will bring the chaplain with me.

> I: So you just said you just had one of those today, so what was that like?

> Sophia: You know it's interesting because people come with a lot of hope, and they did talk about hope in the meeting. The chaplain was able to say sometimes hope changes and hope goes from hope to a cure, hope for time, and hope for peace. I think because those words came from a chaplain, it was more comfort to the family and the patient. Because they know that the chaplain is not medical, she is faith driven, they are probably more accepting, because there might be a mistrust of the medical team right now. But when they acknowledge peace, something that people get spiritually from their God, their Buddha, whoever that might be, I think it opens up a dialogue for me as a

nurse practitioner where I can say well we are not able to cure this but we can provide comfort…. The chaplain promised the wife that someone from their department would see her husband each shift for prayer and support. Nothing can be more valuable to families when they can't be here around the clock than a promise that someone will be here to pray and hold the hand of their loved one. That was at the end of the meeting, the patient is now comfort measures only.

Sophia values the close working relationship she has with the pastoral care department. As a nurse expert she sees a bigger picture and recognizes that agency in expertise involves an interdisciplinary team approach. She views the chaplain as a valuable presence not limited to offering spiritual peace or the promise of abiding presence alone. She views the chaplain as a source of building trust, assisting with decision making and creating space for her as nurse practitioner to continue in a dialogue of how best to provide comfort for individuals and their families.

Being with chaplains in the context of inpatient palliative care setting also enables the nurse with a mentoring relationship which adds to their own repertoire of spiritual care skills. Some of the nurses report learning nuances of spiritual care by listening to and modeling the behaviors of chaplains they work with. Lucy one of the nurses in this study discussed how she is often in a situation when someone dies and the chaplain is not available or the family declines their service. However in the death moment she is the one left to help with closure before the family leaves the hospital. She often models the chaplain to help her meet spiritual needs at those times. She carries a small collection of secular and sacred literature and poetry that she utilizes when appropriate. She is comfortable with prayer yet modest when discussing her ability to weave thoughtful words carefully together to offer peace at end of life.

Lucy: My prayers are something that I would like to get some help with, so that I can pray more spontaneously… And I also get too emotional, when I do a prayer I almost always tear up, I choke up a little bit, and I'd like to be able to pray just like the chaplains do… I often know the family a lot better than she would in many cases, but she can come in and she can just observe for ten minutes, and then put together pieces of that observation that come out in her prayer. I would really like to be able to work on that, and to be able to do that.

I: Well that's not easy to do when you're in the trenches with someone. Chaplains often enter episodically with less frequency than nurses. Plus they are trained in the literary and theological arts. They know how to weave language and pick up on major themes and they don't always have the same emotional investment that you have.

Lucy: That's true.

I: So don't be too hard on yourself because even when you know how to do that, and you've been trained to do that, when you're involved with the people you still tend to want to cry, because it's your loss too. The shortest but perhaps most poignant verse in the entire Bible is "Jesus wept." Every time you develop a relationship with a family member or a patient and then they die, that's a little death for you, because if you've really been effective, if you haven't faked it, there's a part of you, there's a piece of you in that relationship that's now…

Lucy: Severed.

I: Yes, severed, so you would only be in denial if you did not to feel that, and that's what makes this job so draining when you have this over and over again.

Lucy values the healing presence and carefully crafted words that chaplains provide at the most difficult times in life. Young and Koopsen (2011) point out that only 20% of hospitalized patients in the United States see a chaplain. There are not enough employed chaplains to meet the spiritual care needs of hospitalized patients, they are also often the first to be cut under financial constraints. Lucy as one who is often the last person in the hospital setting to provide spiritual care at end of life humbly carries with her a booklet of eloquent poems and prayers. She is prepared

when called upon, hoping to meet those needs while simultaneously experiencing grief for those she has formed attachment and has cared for.

The nurses in this study are clear about their role in spiritual care. Bev, Sophia and Lucy reflected dialogue that highlights their awareness of when they are beyond the scope of their expertise. They operate with a team approach in meeting client and family spiritual care needs. Yet they also recognize the overlap of specific disciplinary knowledge and skills inherit of the nursing role in general. Lee Shulman, (2010) eloquently describes this overlap in the forword [sic] of *Educating Nurses: A Call for Radical Transformation.* He names nursing as a hybrid profession and one that is reflective of the attributes of other professions while maintaining a unique identity of its own. The nurses in this study draw insight and knowledge from many disciplines to inform their practice and provide care at end of life. This again points to the Benner model (2009) of expert agency as working in and through others to provide the care their clients need and desire. Ministry and pastoral care are highlighted as the discipline which informs much of these nurses spiritual care practices. This knowledge is utilized through a team approach as well as in isolation with their clients.

The nurses in this study represent a humbled expert stance while offering care and comfort at end of life. They embody spiritual skills of caring that include presence, courage, silence, touch, and empathy. They manifest the desire for a good and peaceful death on all levels including the physical, psychosocial and spiritual realms. To accomplish this they engage the interdisciplinary team. They know when they are

beyond the scope of their practice and accept limitations and obstacles they alone cannot surmount. In service to others they describe a mutuality of care, a reciprocal phenomenon present in the caring relationship. In other words they get as much as they give and describe their role as one of "gift, privilege and honor." Their experience in life and in practice has enlarged and enlivened their perspective of life and offered these nurses more unique and refined ways to respond to suffering. Palliative care nurses in this study articulated the awareness of the fragility of life, the essence of spirituality and whole persons, the experience of suffering and the deep human need for connectedness. They respond with profound advocacy and agency illuminated in multiple ways for their patients and families. Now let us turn to a discussion on a subtheme of the ABC's of spiritual care that assists with fostering the capacity to embody a humbled expert stance.

The ABC's of Spiritual Care

I discussed my own background meanings and understandings in chapter three. I spoke about what I expected to see through this research. I named some critical concepts on attitudes, behaviors and communal skills of palliative care nurses and named them the ABC's of spiritual care. They included, A) Attitudes of honor and privilege, trust, confidence, courage, compassion, empathy, respect, and self awareness. B) Behaviors include, advocacy, being present, promise keeping, acts of kindness and touch including alleviation of symptoms and pain associated with suffering and C) Communal skills that include coordination of care, connecting, communication, engagement of grief, promotion of patient and family narratives or

storytelling, and involvement of family in the care of their loved one. I expected these attitudes, behaviors and communal skills would surface in the context of interviewing palliative care nurses because I have previously served professionally in this role. Certainly these features have been highlighted through the presentation of the paradigm case on expertise and exemplar of proficiency in chapter four as well as through first half of this chapter and the discussion on the humbled expert. Yet in addition to presenting the humbled expert theme it becomes important to illuminate findings that came out this research that add to the theme and understanding of nursing practice in this setting.

The following discussion involves additional attitudes, behaviors and communal skill concepts that came directly from the interviews. I consider them sub subthemes on the ABC's of spiritual care that also enhance and undergird the notion of the humbled expert while adding to our understanding of how nurses provide spiritual care. The goal of interpretive research is to reveal hidden meaning that adds to our understanding. Not only did the following aspects of spiritual care elude me when describing my fore structure, these features are not all explicitly well articulated in the spiritual care nursing literature. I assume that this is because they are either taken for granted or unknown. The first subtheme I will discuss is the attitude of openness to otherness the following selected excerpts help to illuminate this finding.

The Attitude of Openness to Otherness

> Jane: So what I have learned through my own walk in life and work is to walk in with an open mind and let the patient guide me. If they invite me I can keep walking with them, but it's really fine tuning my antennas and letting them lead me.

Sophia: I believe spiritual care includes but is beyond just religious knowing. I know that because of my experience in hospice, home care, and inpatient palliative care. I've met many people that say I am spiritual but I do not necessarily believe in God. For a while I was like how can this be? But then coming to meet these people…you understand that they have their own beliefs and a spirit they have within themselves. Their God might no one or somebody else; it does not necessarily have to be the God that I know. I do think I've evolved, and it's openness…. I am a Christian…I have Jewish friends and we live in a religiously diverse community and my son grew up with a lot of Jewish friends and we knew Bat mitzvahs, I went to Shiva's. So you open yourself and I evolved to accept people where they are, who they are and I have a comfort with that, speaking to any religion or faith.

Donna: When dealing with families I tell the staff, don't go by your first impressions, and keep an open mind because there are a lot of things and the way people cope and the family dynamics that we do not always know or understand. There is always more that what you see on the surface.

Bev: Yesterday we had an experience; it was a 44 year old AIDS patient that I only knew since Tuesday he was still planning on his birthday party in a few weeks with 150 people coming from around the country. He knew he was moving towards end of life and wanted this one last birthday party with everybody. His partner was here with him. Yesterday his clinical condition worsened, and he made the decision about 3-3:30 in the afternoon that he was done, and all he wanted was chocolate milk and Dilaudid… and we accommodated both of them, he died just before 6:00 pm. It was a very quick death, but yet I feel from a spiritual standpoint he was taken care of…. We did not have a chaplain because he made that decision, he knew what he wanted. He wanted to be alone with his partner rather than involve more team care members. I felt that was very much a spiritual part of who he was…and his life and talking to his partner when he was taking his last breaths, and acknowledging their need to be together. A lot of people may not have felt comfortable with the diagnosis, the gay relationship and his partner and all of that. Yet I felt privileged to be with them. I think that was all part of spiritual care.

Spiritual care involves an attitude of the nurse as being open and allowing patients and families to lead the nurse in a growing understanding and grasp of what is meaningful to their clients. This openness fosters a relationship that begets and

creates a clearing of openness for patients and families to disclose what they want and need. Jane describes this as "invitation" and her "fine tuning of antennas" permit her to co-journey with others and provide care. According to the Merriam-Webster on line dictionary (www.merriam-webster.com), the term *open*, involves moving from a closed or shut position to make accessible or available. Donna is aware of this and reminds other staff to "keep an open mind" to reserve judgment especially when dealing with families and their interactions because people cope in a variety of ways and care providers do not always know why certain situations and actions of family members exist. Bev's experience reveals how being open enhances the nurse patient relationship, and creates possibilities for facilitating the beliefs, values and lifestyles of others.

This openness is often implied in the spiritual care literature as respecting diversity (Taylor, 2002; Young & Koopsen, 2011). While respect is certainly an attitude that is important and also emerged in the dialogues of this study it does not quite capture the same meaning as being open. For instance, one can respect another person without making available or accessible the things that give meaning and value to their life. While these distinctions may seem minimal I believe it is important to highlight the difference as in the case described by Bev. Her openness permitted meaning for a couple who might otherwise be disenfranchised at end of life.

Sophia represented many of the nurses in this study who all spoke to an evolving understanding of the need to be open and non-judgmental when dealing with the beliefs, values and lifestyles of others. It is through the respect of others and

engagement of relationship that these nurses evolved an open understanding and

acceptance of others. This openness creates the possibility of facilitating or bringing

the values and beliefs of others into the care environment. It is easy to facilitate care

for people that have very similar beliefs, roles, lifestyles, economic and social

similarities, as well as cultural and religious understandings. Yet being open to others

is requisite for the full agency described by Benner and facilitating care for those that

perhaps diverge and differ from the person providing care. Respecting diversity is key

for nursing in any setting but an attitude of openness permits taking action on the

behalf of another when providing spiritual care for persons with diverse cultural and

religious backgrounds. Attitudes beget behaviors and the following discussion reveals

the behavior of careful assessment and how this behavior assists with providing

spiritual care. The following excerpt from Bev picks up from the last one with Bev

but highlights assessment.

> I: Well back up a little, because you kind of glossed over this, you said
> something about the plan changing, the situation changed. You realized that
> this man was dying more quickly than you thought. This whole original plan
> was his birthday party but how did you know to switch gears?
>
> Bev: Because of his clinical signs, as a nurse it was easy… We had a
> thorocentesis that morning and he had done well immediately, but then he
> went into cardiac tamponade. He started struggling, we called the rapid
> response team, and then we knew…He was cognitive and able to make his
> own decisions, and he made it, we confirmed it a couple of times. I confirmed
> it with him specifically at one point, that he was ready to die and he wanted
> chocolate milk and Dilaudid. So it was easy to know we were changing gears
> because there were clinical signs.

Examining expertise in practice involved looking closely at the Benner et al.

(2009) model of expert nurse as discussed chapter four. Benner highlights a finding

about expert nurses in that they use assessment language at a minimum, they no longer work consciously from rules or maxims. They function from past experience and respond without reflection and an embodied know-how. Advanced clinical grasp and embodied know, enables the nurse to see the unexpected and respond in a timely fashion. Bev reiterates this by saying "it was easy to know" things were changing based on clinical signs and she did not give an account of the assessment of those clinical signs. Bev's narrative is an exemplar of the phenomena that expert nurses use assessment language at a minimum. Given her patients clinical condition, Bev quickly confirmed his desires and proceeded to ensure that his spiritual needs were met and in congruence with his clinical condition. This fluidity of practice and precision of assessment often seems effortless yet with probing questions the careful assessment behaviors of expert nurses became visible. Bev's embodied precision of assessment enabled her to facilitate a peaceful and dignified end of life experience for this couple.

It is important to underscore the careful assessment that expert palliative care nurses do make in attempting to meet spiritual care needs as this can often be taken for granted at the expert level. I have chosen to illuminate the behavior of careful assessment these nurses revealed for meeting patient and family spiritual needs. Young and Koopsen, (2011) discuss the importance of health care providers in recognizing the specific beliefs, rituals, practice or perspectives that are meaningful to clients. Careful assessment is required to make those factors known as well as humbly utilizing the client's own self-transcendent resources to bring hope and healing to patients and their families. The nurses in this study spoke directly to assessment and

how this assists with facilitating a dignified and peaceful end of life. The following excerpts highlight this finding.

Behaviors of Careful Assessment

>Cindy: It's very individualized. You have to just go in and assess each person and start from scratch, like a blank slate because you just don't know. You have some patients who, you even mention anything spiritual they become defensive, or you have some who want you to pray with them every time you're with them, you just never know… You have to be prepared for whatever they need. I very much believe in honoring what they're comfortable with. I think that's because I wouldn't want anyone to push anything on me that I wasn't comfortable with. So I just try to be very aware of what they need and what they want.

>Vicki: Well it's honoring, it's finding out what's important to them, what it is that they need to accomplish to feel like their life was meaningful. Maybe they need to make peace with someone, it is all so personal. I am amazed what people tell me. When they come to the hospital and they're dying you have to talk and you have to listen and sometimes you have to figure it out for yourself because they don't always know how to tell you…. We've all grown up with different customs and different religious backgrounds, different backgrounds of all kinds. Sometimes they're suffering from spiritual pain and not necessarily physical pain, and maybe it's due to the fact that they have fallen away from their religion and they can't see themselves as getting back from whatever happened. I had a patient before that had been a very devout catholic, but then decided that she was gay and could no longer practice her beliefs in the Catholic Church…. This causes a lot of mixed feelings because those beliefs are ingrained in your body and soul. If you're kicked out, where you go from there? It's kind of like a little lost soul out there floating around. We have to find another source of strength and hope for them.

>Betty: It all just comes from my talking with them and doing my assessment. We talk about quality of life, strengths and weakness, fears, trust, comfort, peace, hope, dreams, what brings people comfort, what makes them get up in the morning, what makes them go from day to day, what gives them strength.

>I: How about families, how do you assess their needs?

Betty: Same thing, because they're going to have different fears and strengths and different goals and dreams, but they all are the same types of things.

Sophia: Well a lot of times I'm involved in goals of care conversations with family and families will acknowledge what their beliefs are as far as miracles and God's will and I think it is my knowledge of different faiths and religions that I can interject and talk with families honestly. What is there in the Bible that we believe as Christians? I have a comfort level with that.

I: So you're not afraid to get into those subjects because you feel like you've got the background?

Sophia: Not at all. You have to have the background for it, and I can tell you that I've never had a problem with it because patients families will say they want a miracle, she's gonna get off the machines. I say well you know, I acknowledge miracles and God's ability to provide that…. But I always try to say that what we have are tools, the machines are tools, this drip is a tool, these are tools. When these tools become futile we can acknowledge that God doesn't need tools. So you have to have a comfort level there, and respect, having the timing to respect when it's appropriate to go there.

Donna: I remember one patient who was not responsive, but his wife was concerned about letting him go, because their church had taught that they must do everything to keep somebody alive. If she did anything otherwise, then that would be a terrible wrongdoing. I did try different things over different days. The one thing that worked for this person in particular was asking her what specifically her beliefs were… I then offered her the possibility to consider that maybe God gave her this opportunity to say good-bye to him. God is ready for him but God is giving you time… God is very merciful and very compassionate and knows how hard this is for you. So God is giving you the opportunity and is not going to take him away until you're ready to let him go…. That seemed to help her, she felt like oh, okay, I believe that, I can accept that, and okay, I'm ready to let him go. She felt like somehow she now had God's permission to let go, and that was a shot in the dark.

I: Well not so much, because you're actually trying to find out what the person believes, and create harmony with the circumstances and decisions that surround them.

Donna: That's a very good way of putting it but yes, that's what I try to do.

I: So you try to make sure that when someone is in conflict, it cues you that there's this unrest, and the way you go about helping is to revisit beliefs?

Donna: I guess revisit, and to me maybe reframe the situation, instead of it being I can do nothing, I'm powerless, this is all up to God, maybe reframe the situation as well. Maybe God cares about you too, maybe God's thinking about you, and it doesn't just affect him, it affects you too, and God's here for you also. This helped her with the decisions she had to make.

Assessment becomes paramount in spiritual care at end of life. Certainly

perceptual acuity and intuition make agency possible and reflect expertise in practice

but it is impossible to know what people believe, value or desire without good

communication and assessment skills. Compassion, empathy, respect, and openness

are embodied attitudes that pave the way for careful assessment and this in turn leads

to helping people cope and make decisions about end of life care that are in harmony

with their beliefs and values. Vicki pointed out that it may even be possible for people

to transcend beliefs that have caused dislocation or exclusion through the caring

relationship experienced with nurses at end of life. In addition, Bev spoke about

supporting religious beliefs that are not the same as hers. She at times has conflict

with this personally, yet she is fully aware that her role is to support and advocate for

others no matter what their beliefs are and their decisions may be.

Bev: This is where I the nurse had to realize my role was to support, and engage the entire team. This was an Orthodox Jewish man in his 70's who had post polio and this family, a wife, three children, very Orthodox Jewish, all of them. Their belief being that not only do you not withdraw but you do not withhold treatment. They had rabbi's that came in and met with us… a couple different rabbi's from New York that were the experts for them and giving information over the phone. This patient was with us over a six month period. We couldn't withdraw, we couldn't withhold so we did CPR. From the standpoint of our role as healthcare team providers this turned out well because the patient and family were supported all the way through

this….From my personal viewpoint, the fact that we had to do CPR on this man is sad, because I hate that this had to happen because we all know what transpires. But yet when the family looks back on it, they are appreciative. The wife came back to thank us, and the daughter even invited some of us to her wedding. So they felt very positive even though we had multiple difficult discussions, they felt the support from all of us for their religious beliefs.

Openness, careful assessment and facilitating the beliefs, values and desires of others are key elements in end of life spiritual care. This becomes possible through sophisticated levels of involvement with clients and their families. Enhanced advocacy and agency pave the way, guide and empower those faced with life limiting illness and end of life. This agency works paradoxically at end of life to offer a sense of control over situations that are often fraught with helplessness, hopelessness and lack of control. Through openness and careful assessment nurses are able to personalize care and empower clients undergoing loss. The communal skill of empowering patient and families can offer sustenance, healing, reconciliation and peace for patient and families and is highlighted in the following excerpts.

Communal Skill of Empowerment

Jane: it's kind of an evaluation of assessing where that patient is and getting to know what kind of person they are, and to give control back to them. Get their pain under control… or something else that is out of control. For me spiritual care is assessing and evaluating their sense of peace, because I'm walking in and it's usually drama and chaos and fear and emotion and anger. When I'm walking away there are hugs and tears of thanks and there's this overwhelming sense of peace. So my life while it may not be normal or even ending I have some control over my life… so it's giving patient and families options.

Melissa: I try to get to know my families so I know what their values and beliefs are. It's very important, I know culturally too, but I'm more focused on what their lifestyle is and their meaning of life is, because especially the elderly, they'll talk about it. Sometimes family members, younger family

members aren't as receptive to discussing it because it's very emotional, I mean we're talking about our mortality… some people don't want to go there. So I try to get in the habit of asking if we can talk about it, if it would be okay to talk about instead of just barging in, get permission from them. It is really hard for people who are in the hospital, they lose all their control. I even said to somebody who was at odds with their physician you know, you're the captain of the ship. People need to know that choices about their life and death is their decision to make, it's not ours.

Vicki: I feel bad for patients when they come to the hospital because they're just pushed. Things are done to them and once you start something it's a snowball effect and they lose their ability to make decisions… They're just lost in the system. This is where palliative care often comes in…

Sophia: I think my experience working on a bone marrow transplant floor greatly influenced me because we did clinical trials…We'd give people chemo up to the day they died, but we did not have anything in place for the families to allow patients to say okay, I'm done, I'd like to go home with hospice 2-3 weeks before they'd die. We just would treat, treat, treat and keep them there, and unfortunately we are, well it's fortunate, we are a comprehensive cancer center. People come here from all over the Midwest, 250 miles, they come expecting clinical trials, fine, but if it's not working maybe we need to sit down and have goals of care conversation.... I went to a hospice and palliative medicine meeting and this lady wrote boating on the board. B-efore O-ffering A-nother T-reatment I-dentify N-ew G-oals because maybe the patient might say I don't think I want that right now. I might want to go home… I saw that on bone marrow transplant with leukemia and lymphoma patients they do not always have those conversations… and that's really what I think pushed me that there is going to have to be a difference here.

Lucy: I think, and then in this case, with the family with the melanoma, they've been to MD Anderson and across the country, rightfully so, young guy with melanoma… So they've done already a lot of things that most people don't or can't do….The wife said we always tried to have control over this disease and now it's so hard to let go of that control. So the only thing I could do was to refocus control… it now goes to the only thing that we can control at this point and that's making him comfortable and how in this last piece of time, however long it is, how can we provide this.

I: This very special task of spiritual caring, you talked about being able to read the family members, being able to know what will help and what won't. Tell me more about the palliative care room you have here and how you think it's effective, or maybe things that you don't like about it?

Lucy: You know, just two hours ago I took a family through that room, and this is a family that's young, 52 year old man who's dying from melanoma. They are really having a difficult time trying to figure out is there still more that we can do in terms of trying to make him better? Well we're at that point where there's nothing, and so I spent really the majority of the morning with that family. We talked…the doctor came and talked with us, we went and looked at the room... and then we changed code status. Tomorrow morning now he's going to move into the palliative care room. I can tell you that his wife, son and her two parents walked into the room and said it feels so good…. It's bright, but it's soft, it's comforting, it's spacious. The TV, stereo, DVD, books, lighting and furniture…it's equipped so that the family can spend the night easily. I always call it a combination hotel room/hospital room. You've got this very nice room, but you've also got the hospital staff that comes in, business as usual. So it's really the best of both worlds. The fact that is right next to the waiting room makes it perfect for over flow of friends or if family needs a break but want to be close by…. So I think it's perfect. We are in the process of creating another room that will be specific to isolation patients that can be deep cleaned. The comments that I've had from family members are just kind of wow, this is so nice. Once again, I think that what's coming across to that family member is this is a really, really special time when this person that you love is dying and we really want to make it as good as possible, and this is part of that piece, physically making it as good as possible and they really appreciate that.

I: It's so hard to envision losing your loved one, and I don't think it fully hits until they're gone. Do you think the physical environment helps engage the fact that this is really happening in a civil and compassionate way?

Lucy: Yes, accepting that this is what's happening. I think that's very true. It's kind of a different step, we're now moving you into this room, and when you come into this room things change. We're not going to be drawing blood, taking vital signs routinely. Things are done differently in this room.

I: Kind of like a delivery room almost. I mean I know many institutions have changed labor and delivery back to where you deliver in the same room you

labor in, to make it more like home, where this room is also to make it more like home.

Lucy: Exactly, absolutely. And that's funny that you should say the delivery room because I've tried to, you know, over and over again, somebody will say well what does a palliative nurse do and I've tried to come up with my best answer to that and it's not an easy answer. I decided, just this morning as a matter of fact, that I think a nice answer is, we do what a midwife does only on the opposite end of the spectrum. A midwife, in the old days, and even now, is called in to make the birth as safe and comfortable, and as pleasant as possible. So this is the opposite, it's the very end of that person's life, and our job is to make it safe and comfortable, and as memorable as possible.

Creating a "sacred space" for others to be safe and comfortable applies to the exterior environment as well as the interior of a person's being and all which offer meaning and hope (O'Brien, 2008; Young & Koopsen, 2011). All of the nurses in this study discussed the importance of the external and internal environment associated with inpatient palliative care at end of life. Lucy is fortunate to have a palliative care room specifically designed to contextually engage and support the work of dying for patient and family. Carefully appointed lighting and fixtures with colors of green, gold, purple, white and red fill this room. Pictures of seasons and nature elements of water, stone, rock and wood add to the beauty while implicitly conveying that all living creatures share a cycle of life. The physical environment sends a message to patients and families about the culture of the hospital and a dedication to and participation with hospitality and care. The room clearly makes a statement that something unique is occurring and care has been taken to make this experience safe, comfortable, meaningful and memorable. The external environment along with the personalization of care through the openness, assessment and empowering nature of the humbled expert nurse makes spiritual caring at end of life a concrete reality.

A Synthesis of Themes

The relational I and Thou stance empowers patients and families to be an active voice during the illness trajectory and through end of life. Empowering clients is what quality palliative care is all about (Matzo & Sherman, 2001). This certainly adds to the spiritual care and confidence of others that no matter how difficult it is to move from life to death or to lose a loved one, getting through this is not insurmountable. As persons move through life limiting illness and approach death, spiritual suffering is heightened. Losses amplify related to the disintegration of one's identity and purpose intensifying as death approaches (Zerwekh, 2006). Spiritual care involves humbly approaching others with an attitude of openness. This open relational stance assists nurses in performing a careful assessment in order to engage individual beliefs, perceptions and practices while implementing this into the care environment. Whether it is through religious or non religious language, spiritual care empowers and assists clients to transcend the hopelessness and powerlessness associated with culminating losses. The following excerpt from Jane helps to summarize and synthesize the theme of humbled expert. Her excerpt reveals the "I and Thou" relational stance, attitude of openness, careful assessment, and empowerment that are integrated and held in delicate tension while providing spiritual inpatient palliative care.

> Jane: I know after having eyes open, ears open, heart open, I know that I'm on a right path and I'm just trying as those books say 'Don't sweat the small stuff' because we're not large and in charge. We might think we're large and in charge but I have a very strong faith as a result of all of these things since I started palliative care and I think we're on a mission. I'm just a vehicle that is

here to help. I think that's our gift, that one of many reasons why we get to provide palliative care, you know, not just at end of life, but I think that's one of our gifts is to provide a bridge…. Our role is to increase communication, to educate, because so many of our families don't understand what's going on. Our patients are scared. There are so many opportunities for education that our staff nurses don't have time, and I don't know that they even know what to do during that time. Our physicians haven't been educated on end of life, they don't even know what to do, and they don't have that time or often don't see the need for education at this time…But to answer your question, have I been present or been involved with patients at end of life and have things gone smoothly? Yes. And it's really spending that time with the patient alone, spending that time with the family alone, and assessing both of their needs and their perceptions and getting what they need and bringing that into their care and bringing them together, it's beautiful…. Sometimes people need closure at that end of life and it's getting what I think I felt when I experienced end of life with my father. I got some closure on things that I dealt with in my life, of anger, and family conflict. I was able to forgive my father for his verbal abuse before he died. Ironically the things he said to me actually gave me a drive to be all that he said I would never be. It turned out that my dad didn't even remember saying things that hurt me. Our families need that same opportunity and our patients need to know that they made a difference in this world and that they did a good job with their children or whatever that they were striving for. I feel like we do a good job in preparing the patient and the family and it's so much smoother than when palliative care is not involved. That has been confirmed by our oncology area, they openly acknowledge that they need palliative care involved with all of end of life because there's high drama, high anxiety, anger, fear, very emotional situations when we're not involved, in their eyes. So it's nice to hear that we can make a difference.

Summary

As humbled experts, the nurses in this study offer spiritual care through sustenance, healing, guidance, and reconciliation of relationships that are inclusive of God, self, and others. They accomplish this by maintaining an I and thou relational stance, and wisdom to enlist other experts. Their attitude of openness, behavior of careful assessment, and communal skill of empowering patients and their families transforms the traditional experience of end of life institutional care. Making a

difference for people at end of life is something that palliative care has aspired to

since the hospice movement began in Great Britain. As that movement grew and

crossed continents elements of spiritual care were bound with it. Early in this

dissertation I cited Dobratz, (2005) who spoke about palliative care emerging and a

debate that continues of whether inpatient palliative care is associated with the

medical model or embodies the philosophy and goals of hospice and quality end of

life care. The nurses I interviewed for this study definitely put to rest notions of

oppression that patients and families might experience through the inpatient palliative

care experience. All of the participants in this study articulate their unique inpatient

palliative care nursing role as holistic, transforming and adding to the quality of life

for persons under going loss. Sophia a nurse practitioner and for prescriptive reasons

trained under the medical model completely recognizes the role of providing spiritual

care at end of life as a unique aspect the nursing profession illuminated in this

excerpt.

> Sophia: Well reading Nightingale, Cicely Sanders, and I bet you people do not know that Florence Walls started the first hospice in Connecticut, a nurse, and dean of Yale nursing. It all comes from nursing, let's keep it! The medical will be the medical but it will come from nursing to care for patients spiritually at end of life… The more you know, the better you care for your patients, so just being prepared, you have to read and you have to look at new things, and you have to think about and enjoy what you do. To know we can make a difference it is just wonderful. My biggest concern is that I'm getting old. I don't know about the younger nurses coming on, we'll see…. I love being a nurse, I wouldn't do anything else. They should pay me more (laughing) but I love being a nurse.

Being a nurse and especially offering spiritual care at end of life means engaging

suffering and loss that few people witness in one lifetime. The astute perceptual skill

and tacit knowing of expert nurses providing spiritual care at end of life are often

hidden in the unassuming posture of humility. Yet it is this very stance that permits

and actualizes the spiritual aspects of care. This level of agency requires putting

another first, being sensitive and caring about what matters to others and moving

beyond the status quo to transform the care environment with the best ethical,

aesthetic, personal, empirical and emancipatory ways known to nursing. It is through

the humbled expert nurse that patients and families experience grace instead of

awkwardness, comfort instead of suffering, hope instead of despair and a paradoxical

peace that transcends all understanding. It is with great joy, honor and privilege that

these nurses share their "gifts" with humanity and while ministering to a world in

deep need of care they reciprocally experience love.

Implications for Nursing Practice

This study explored the cultivation and nursing practice of spiritual care at end of life in an inpatient palliative care setting. The paradigm case on expertise along with the exemplar of proficiency in practice adds to our understanding of skill acquisition and implementation of spiritual care. The humbled expert and associated subthemes of I and Thou relational stance, enlisting other experts and concepts on attitudes, behaviors, and communal skills of inpatient palliative care nurses further illuminates the personhood and practice of inpatient palliative care nurses. Standards of care that are articulated in the literature by Jennings (1997) as palliation and the relief of suffering, enhancing autonomy and personal control, and healing or making whole permeate this study. The dissemination of these conclusions may assist nurses and other healthcare providers with newfound understandings for engaging assessing, implementing and evaluating end of life spiritual care.

This study is unique in that it examined the personhood and spiritual care practices of inpatient palliative care nurses. This specialty is relatively new as these programs have emerged in the US within the last decade. Many of the nurses in this study are among the first to develop and implement an inpatient palliative care program within their respective places of work. No other nursing research to my knowledge address the subject of spiritual care within this context or tackles the development of astute and tacit skill involved in providing spiritual care.

This study has implications in the direct setting of inpatient palliative care at end of life as well as indirectly for end of life care at large. Directly the way in which

patients are engaged and cared for spiritually at end of life relates to the quality of care, both perceived and received in the institutional health care setting. This research helps to illuminate that inpatient palliative care programs are poised to meet the spiritual needs of patients and families at end of life. Expert nurses working in this setting possess astute, practical and tacit skills of engagement and facilitate care that embraces personalization while creating a context for a meaningful, peaceful and dignified death. Rather than discard or abandon those with whom we cannot cure or restore to health, inpatient palliative care nursing actualizes the reality that healing exits beyond cure and health can be fostered and maintained throughout and until the end of the life.

Engaging the work of dying and attending to the spiritual aspects of human existence permits the acceptance of our finite form and fosters healthy ways for acknowledging, celebrating and grieving the human condition. Spiritual care indirectly may positively impact the current health care crisis and billions of dollars being spent yearly in this country. "Last year, Medicare paid $55 billion just for doctor and hospital bills during the last two months of patients' lives. That's more than the budget for the Department of Homeland Security, or the Department of Education. And it has been estimated that 20 to 30 percent of these medical expenses may have had no meaningful impact" (www.cbsnews.com.60min). Expert spiritual nursing care may assist with decreasing futile prolonging of suffering and death by compassionately addressing the spiritual and existential concerns of human existence during and throughout life limiting illness.

The explication of caring practices offered in the narratives of this study assist individuals and institutions with moving spiritual caring from out of the margins by publicly acknowledging the practical, ethical and moral value of nursing care at end of life. The examination of exemplary caring relationships provided through this study may also serve to prompt and promote structures and policies that support the continuation and development of inpatient palliative care providers and programs.

Finally this study has implications for nurses working in this setting and the emotional drain of confronting grief and loss on a daily basis. It can never be taken for granted that personal spiritual care exists for the caregiver. Also many of the nurses in this study reported challenging relationships with physicians that for undeclared reasons resist palliative care and add to the stress of this demanding role. Support systems need to be in place that directly address and promote healthy ways of coping and a means for the nurses themselves to restore their soul.

Implications for Nursing Education

This study directly points to the need for education in spiritual care to be incorporated into the curriculum of nursing education. Multiple opportunities exist for educators to engage and practice the art of spiritual caring that is not limited to end of life. Case studies, role play, simulation, verbatim analysis, film analysis, script writing, and care planning that engage existential and spiritual concerns of patient and families are just a few ways to begin the discussion and assist novice nurses with developing these skills. Art, literature, music, nature, storytelling, reflective journaling, and dream work are tangible ways according to Taylor (2002) to

implement spiritual care for clients. These same features also present an opportunity for faculty to promote spiritual awareness and self care as students traverse through the rigors of nursing education.

Assessment came through boldly in this study as essential for the personalization of care. However the absence of using formal spiritual assessment tools was pervasive with the sample studied. The nurses reported knowledge of these tools but preferred conversational methods for assessing patient and family needs. Documentation and evaluation of this care was also informal and generally not done or minimally reported through progress notes. This study reveals the importance of educating practitioners on the effective use of these widely available tools. Spiritual assessment tools provide a comprehensive inquiry on spiritual and existential concerns. They also assist practitioners with systematic documentation and evaluation of the care they often spend hours delivering yet often is not reflected in the patient record.

This study has implications for the education of staff nurses working in the hospital or community setting in terms promoting the evolution of nursing care expertise. Rubin (2009) points out nurses are at risk of being stuck in unchanging levels of practice that impede clinical knowledge and ethical practice. Spiritual care education, dialogue, and an equal balance of challenge and support can make a tremendous difference particularly for the proficient nurse evolving toward expertise.

Directions for Further Research

This study focused on nurses practicing an inpatient palliative care setting and represents the nurse's perspective. Additional study with focus groups and or observation of nurses practicing spiritual care at end of life may reinforce and add to the findings of this study. Additional clinical studies on client and family member's perceptions of spiritual care in an inpatient palliative setting is also needed.

Further research with grounded theory methodology (Glaser & Strauss, 1967) may assist with formalizing concepts such as the ABC's of spiritual care. This inductive method would assist with resolving the primary concerns of participants practicing and receiving care in this area through systematic theory generation. This type of research can be pursed with qualitative and or quantitative data.

This study reinforces the concept that not all scientific nursing knowledge branches from a Cartesian rationalist subject to object, positivist framework. Interpretive phenomenology points to our historical, cultural and socially embedded practices that exist based on what matters, what is effective and dynamic in nature. Nursing as both art and science relies on theory based knowing as well as intuitive and tacit knowledge and skills for care. Personal, ethical, aesthetic, empirical, and emancipatory knowledge are fused and embedded in expert spiritual caring. They function together to permit agency and expertise in nursing practice. Spiritual care can never be prescriptive or universally applied. The expert tacit skill demonstrated in this study reflects the nurse's humbled stance in relationship to others. Through openness, assessing and implementing of diverse individualized transcendent

meaning and concerns, others are empowered and experience quality care at end of life.

Conclusion

The data provided by the nurses in this study were amazingly deep and rich. It was a pleasure to engage a dialogue that for all of us provided a ground for remembering, being present with, and envisioning expert spiritual care. Listening to these transcripts was like listening to a choir. Unique voices emerged at point and counterpoint but together there was a harmony and unison of spiritual care that rang out loud and beautifully. I am so grateful for their gift and song. Near the completion of this study I received a birthday poem from my brother Tom and serendipitously it fit both my subject and method for this study. I close with this reflection.

Note

Remember how the naked soul
comes to language
and at once knows
loss and distance and believing

Then for a time it will not run with its old freedom
like a light innocent of measure
but will hearken to how one story becomes another
and will try to tell where they have emerged from
and where they are heading
As though they were its own legend
running before the words and beyond them

through the noise of questions
Love Always,
Thomas

References

Abma, T. (2005). Struggling with the fragility of life: A relational narrative

approach to ethics in palliative nursing. *Nursing Ethics, 12*(4), 337-348.

American Academy of Hospice and Palliative Medicine. (2003). Position statements:

Definitions of palliative care and palliative medicine,

www.aahpm.org/positions/definition.html.

Angen, M. (2000). Evaluating interpretive inquiry: Reviewing the validity debate

and opening the dialogue. *Qualitative Health Research, 19*, 378-395.

Bailey M., Moran, S., & Graham, M. (2009). Creating a spiritual tapestry: nurses'

experiences of delivering spiritual care to patients in an Irish hospice.

International Journal of Palliative Nursing, 15(1), 42-48.

Balboni T., Vanderwerker, L., Block, S., Paulk, M., Lathan, C., Petreet, J., &

Prigerson, H. (2007). Religiousness and spiritual support among advanced

cancer patients and associations with end-of-life treatment preferences and

quality of life. *Journal of Clinical Oncology, 25,* 555-560.

Balboni, T., Paulk, M., Balboni, E., Trice, A., Wright, A., Phelps S., Block, H., &

Priggerson, H. (2009). Advanced cancer and quality of death. *Journal of

Clinical Oncology, 27*, 15.

Benner, P. (1984) *From novice to expert.* Menlo Park, CA: Addison-Wesley

Benner, P. (1994). The tradition and skill of interpretive phenomenology in

studying health, illness, and caring practices. In P. Benner (Ed.) *Interpretive

phenomenology: Embodiment, caring and ethics in health and illness* (pp.

99-128). Thousand Oaks, CA: Sage.

Benner, P., Tanner, C., & Chesla C. (1996). *Expertise in nursing practice: Caring clinical judgment and ethics.* New York, NY: Springer.

Benner, P., Tanner, C., & Chesla C. (2009). *Expertise in nursing practice: Caring clinical judgment and ethics.* (2nd ed.). New York, NY: Springer.

Buber, M. (1958). *I and thou* (Smith Classic Trans.) New York, NY: Macmillan.

Carper, B. (1978). Fundamental patterns of knowing in nursing. *Advances in nursing Science, 1*(1), 13-23.

Center to Advance Palliative Care (CAPC). (2004). *A guide to build a hospital based palliative care program.* www.capc.org

Chibnall, J., Videen, S., Duckro, P., & Miller, D. (2002). Psychosocial-spiritual correlates of death distress in patients with life threatening medical conditions. *Palliative Medicine, 16*, 331-338.

Chinn, P.L. & Kramer, M.K. (2008). *Integrated theory and knowledge development in nursing.* St. Louis, MO: Mosby.

Chochinov, H. M. (2006). Dying, dignity, and new horizons in palliative care end of life care. *Cancer Journal for Clinicians, 56* (2), 84-105.

Chochinov, H. M. & Cann, B. (2005). Interventions to enhance the spiritual aspects of dying. *Journal of Palliative Medicine, 8* (1), 103-115.

Chochinov, H., Hack, T., Hassard, T., Kristjansen, I., McClement, S., Harlos. (2005). Dignity Therapy: A novel psychotherapeutic intervention for patients nearing death. *Journal of Clinical Oncology, 23*, 5520-5525.

Chochinov, H., Hack, T. McClement, S., Harlos, M., Kristjanson, I. (2002). Dignity
    in the terminally ill: An empirical model. *Social Science Medicine, 54*,
    433-443.

Cost of Dying. (2010) Retrieved October 12, from www.cbsnews.com.60min.

Delgado, C. (2005). A discussion of the concept of spirituality. *Nursing Science
    Quarterly*, *18* (2), 157.

deWitt, L. & Ploeg, J. (2006). Critical appraisal of rigor in interpretive
    phenomenological nursing research. *Journal of Advanced Nursing, 55*,
    215- 229.

Dobratz, M. C. (2005). Gently into the light: A call for the critical analysis of end of
    life outcomes. *Advances in Nursing Science, 28* (2), 116-126.

Dreyfus, H. (1991). *Being-in-the-world: A commentary on Heidegger's Being and
    Time, Division I.* Cambridge, MA: M.I.T. Press

Dreyfus, H.L. & Dreyfus, S.E. (2009). The relationship of theory and practice in the
    acquisition of skill. In Benner, P., Tanner, C., & Chesla, C. (Eds.) *Expertise in
    nursing practice: Caring, clinical judgment and practice.* (2nd ed.) New York,
    NY: Springer.

Dunne, J. (1997). *Back to the rough ground.* Notre Dame, IN: Notre Dame Press.

Dykstra, C. (1999). *Growing in the life of faith.* Louisville, KY: Geneva Press.

Eisenberg L. (1997). Disease and illness: Distinctions between professional and
    popular ideas of sickness. *Culture, Medicine and Psychiatry, 1*, 9-23.

Fawcett, J. (2005). *Analysis and evaluation of contemporary nursing knowledge*
    (2nd ed.). Philadelphia, PA: FA Davis Co.

Ferrell, B., & Coyle, N. (2002). An overview of palliative nursing care. *American Journal of Nursing, 102* (5), 26-31.

Freire, P. (1983). *Education for critical consciousness.* NY: Continuum Press.

Freire, P. (2001). *Pedagogy of the Oppressed*. 30th Anniversary ed. New York, NY: Continuum Press.

Frost, R. (1920). *Mountain interval: The road not taken* [www.bartleby.com]

Gadamer, H. (1975). *Truth and method* (Sheed and Ward Ltd., Trans.). NY: Seabury Press.

George, L. (2002). Research design in end –of –life research. *The Gerontologist, 42*, 86-89.

Glaser, B., & Strauss, A., (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Chicago, IL: Adline.

Guido, G. W. (2010). *Nursing care at end of life*. Upper Saddle River, NJ: Pearson.

Guignon, C. (1983). *Heidegger and the problem of knowledge.* Indianapolis, IN: Hackett.

Heidegger, M. (1927/1962). *Being and time. A translation of SEIN UND ZEIT by John Macquarrie and Edward Robinson.* New York, NY: Harper and Row, Incorporated Translated from the German Sein und Zeit, 7th Ed., Neomarius Verlag, Tubingen.

Hughes, J., Tomlinson, A., Blumenthal J., Davidson, J., Sketch, M., & Watkins, L. (2004). Support and religiosity as coping strategies for anxiety in hospitalized cardiac patients. *Annals of Behavioral Medicine 28* (3), 179-185.

Institute of Medicine. (1997). In M. J. Field & C. K. Casel (Eds.) Approaching

Death: Improving care at the end of life. Committee on Care at the end of life,

Division of Health Care Services, Institute of Medicine. Washington, DC:

National Academy Press.

Isaia, D., Parker, V., & Murrow, E. (1999). Spiritual well being among older adults.

Journal of Gerontological Nursing, *8*, 15-21.

Jennings, B. (1997) Individual rights and the human good in hospice. *Hospice*

Journal, 12 (2), 1-7.

Johnston Taylor, E. (2006). Prevalence and associated factors of spiritual needs

among patients with cancer and Family Caregivers. *Oncology Nurse Forum,*

33 (4), 729-735.

Kelly, J. (2004). Spirituality as a coping mechanism. *Dimensions of Critical Care*

Nursing, 23 (4), 162.

Kesserling, A., Chesla, C., & Leonard, V. (2010). Why study caring practices? In

Chan, G., Brykczynski, K., Malone, R., & Benner, P. *Interpretive*

phenomenology in health care research (pp.3-22). Indianapolis, IN: Sigma

Theta Tau International.

Kinsbrunner, B. M. (2005). Palliative care perspectives. In S. C. Brown & S. O. Gray

(Eds.), *Palliative practices an interdisciplinary approach* (pp.3-27). St. Louis,

MO: Mosby.

Knestrick, J. & Lohri-Posey, B. (2005). Spirituality and health perceptions of older

women in rural senior high rise. *Journal of Gerontological Nursing, 31*(10),

44-50.

Koenig, H. George, L. Titus, P. (2004). Religion, spirituality and health in medically ill older patients. *Journal of the American Geriatrics Association, 52,* 554-562.

Kuhn, D. (1996). *The structure of scientific revolutions.* (3rd ed.). Chicago, IL: The University of Chicago Press.

Leonard, V.W. (1994). A Heideggerian phenomenological perspective on the concept of person. In P. Benner (Ed.), *Interpretive phenomenology. Embodiment, caring, and ethics in health and illness* (pp.43-63). Thousand Oaks, CA: Sage.

MacIntyre, A. (1981). *AfterVirtue*. Notre Dame, IN: Notre Dame University Press.

Maietta, R. C. (2006). State of the art: Integrating software with qualitative analysis. In L. Curry, R. Sheild, & T. Wetle (Eds.), *Improving aging and public health research: Qualitative and mixed methods.* (pp. 117-139). Washington, DC: American Public Health Association.

Magee, B. (1987). Husserl, Heidegger and modern existentialism: Dialogue with Hubert Dreyfus. *The great philosophers: An introduction to western philosophy* (pp. 254-277) Oxford, England: Oxford University Press.

McGrath, P. (2003). Spiritual Pain: a comparison of findings from survivors and hospice patients. *American Journal of Hospice and Palliative Care, 20*, 23-33.

MacLaine, S. (1983). http://www.youtube.com/watch?v=WqSEH_bVRz8

McSherry, W., & Cash, K. (2004). The language of spirituality: An emerging taxonomy. *International Journal of Nursing Studies, 41*, 151-161.

Metzger, B., Murphy, R., Eds (1991) Psalm 77 p.739 in *The New Oxford Annotated Bible New Revised Standard Version*, NY: Oxford University Press.

Miller, D., Chibnall, J., Videen, S., & Duckro, P. (2005). Experience for persons with
life-threatening illness: Reducing spiritual, psychological, and death-related
distress in dying patients. *Journal of Palliative Medicine, 8* (2), 333-343.

Merriam-Webster. (2009) Retrieved August 23, 2009, from Merriam-Webster
online dictionary: http://www.merriam-webster.com

Moran, D. (2000). *Introduction to phenomenology.* New York, NY: Routledge.

Morse, J. (1995). Editorial: The significance of saturation. *Qualitative Health
Research, 5*, 147-149.

Morse, J. (2000). Editorial: Determining sample size. *Qualitative Health Research,
10* (1), 3-5.

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA
Sage.

National Hospice and Palliative Care Organization (NHPCO). (1999). *Hospice fact
sheet* (Updated Spring 1999). www.nhpco.org/facts.html.

Nouwen, H. J. (1979). *The wounded healer*. New York, NY: Bantam Doubleday.

O'Brien, M.E. (2008). *Spirituality in nursing: Standing on holy ground* (3rd ed).
Toronto: Jones and Bartlett.

Open. (2010). In *Merriam-Webster Online Dictionary*. Retrieved September 2, 2010,
from http://www.merriam-webster.com/dictionary/open

Packer, M. (1985). Hermeneutic inquiry in the study of human conduct. *American
Psychologist, 40*, 1081-1093.

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand
Oaks, CA: Sage.

Pohlman, S. (2009). Fathering Premature Infants and the Technological Imperative

of the Neonatal Intensive Care Unit: An Interpretive Inquiry. *Advances in*

nursing science, 32(3) E1-E16.

Puchalski, C., Cotton, S., Sherman, S., Mrus, J., Peterman, A. Feinberg,…

Prgament, K. (2006). Spirituality and religion patients with HIV/AIDS.

Journal of General Internal Medicine, 21, 5-13.

Ross, L. A. (1994). Spiritual aspects of nursing. *Journal of Advanced Nursing, 19,*

439-447.

Roter, D. (2000). The medical visit context of treatment decision making and the

therapeutic relationship: *Blackwell Science Ltd Health Expectations 3*, 17-25.

Rubin, J. (2009). Impediments to the development of clinical knowledge and ethical

judgment in critical care nursing. In Benner, P., Tanner, C., & Chesla, C.

(Eds.) *Expertise in nursing practice: Caring, clinical judgment and practice.*

(2nd ed.) New York, NY: Springer.

Sandelowski, M. (1995a). Sample size in qualitative research. *Research in Nursing*

and Health, 18, 179-183.

Sandelowski, M. (1995b). Qualitative analysis: What it is and how to begin. *Research*

in Nursing and Health, 18, 371-375.

Sherman, D.W., & Matzo, M. L. (2001). Changing the experience of dying in

America. In D. W. Sherman and M.L. Matzo (Eds.). *Palliative care nursing*

(xvii-xxiv), New York, NY: Springer.

Sherman, D., Xiang, Y., McSherry, C., Calabrese, M., Parkas, V., & Gatto, M.

(2005).Spiritual well- being as a dimension of quality of life for patients with

advanced cancer and AIDS and their family caregivers: Results of a longitudinal study. *American Journal of Hospice and Palliative Medicine, 22* (5), 349-362.

Shiozaki, M., Morita, T., Hirai, K., Sakaguchi,Y., Shima, Y., (2005). Why are bereaved family members dissatisfied with specialized inpatient palliative care service? A nationwide qualitative study. *Palliative Medicine,* 19, 319-327.

Shulman, L.S. (2010). Forword. In Benner, P., Stuphen, M., Leonard, V., & Day, L. (Ed.), *Educating nurses: A call for radical transformation* (pp. ix-xii). San Francisco, CA: Jossey-Bass.

Sinclair, S., Pereira M., & Raffin, S. (2006). A thematic review of the spirituality literature within palliative care. *Journal of Palliative Care, 9* (2), 464-479.

Smith, B. A. (1999). Ethical and methodological benefits of using a reflexive journal in Hermeneutic-phenomenologic research. *Image, 31,* 359-363.

Spirituality. (2010). In *Merriam-Webster Online Dictionary*. Retrieved July 22, 2009, from http://www.merriam-webster.com/dictionary/spirituality.

Streubert, H. J., & Carpenter, D. R. (1999). *Qualitative Research in nursing* (2nd ed). Philadelphia: Lippincott.

Stuetzie, R., Fletcher, M. (2006). An increase in religiousness/spirituality occurs after HIV diagnosis and predicts slower disease progression over 4 years in people with HIV. *Journal of General Internal Medicine, 21*: 62-68.

Sulmasy, D.P. (2006). Spiritual issues in the care of the dying patients. *Journal of the American Medical Association, 296* (11), 1385-1392.

SUPPORT Principal Investigators (1995). A controlled trial to improve care for the

seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Journal of American Medicine, 274*, 1591-1598.

Taylor E. J. (2002) *Spiritual care: Nursing theory, research and practice.* Upper Saddle River, NJ: Prentice Hall.

Taylor E. J. (2006). Prevalence and associated factors of spiritual needs among patients with cancer and family caregivers. *Oncology Nursing Forum 33* (4), 729-735.

Taylor. E. J., Highfield, M. F., & Amenta, M.O. (1999). Predicators of oncology and hospice nurses' spiritual care perspectives and practices. *Applied Nursing Research, 12*(1), 30-37.

Ternestedt, B., Andershed, M., & Johansson, I. (2002). A good death: development of a nursing model of care. *Journal of Hospice and Palliative Nursing, 4* (3), 153-160.

Tillich, P. (1957). *Systematic theology.* Chicago, IL: University of Chicago Press.

Tomasz, O. R. (2005). Spiritual, religious, and existential aspects of palliative care. *Journal of Palliative Medicine, 8* (2), 392-414.

Tyson, J. R. (1999). *Invitation to Christian spirituality: An ecumenical anthology.* New York, NY: Oxford.

van Manen, M. (1990). *Researching Lived Experience.* NY: State University Press.

Watson J. (1985). *Nursing human science and human care: A theory of nursing.* Norwalk, CT: Appleton-Century Crofts.

Watson, J. (1989). Human caring and suffering: A subjective model for health

sciences. In R.Taylor & J. Watson (Eds.) *They shall not hurt: Human suffering and human caring* (pp.125-135). Boulder, CO: Colorado University Press.

Watson, J. (1990). Transpersonal caring: A transcendent view of person, health, and healing. In M.E. Parker (Ed.), *Nursing Theories in Practice* (pp. 277-288). New York, NY: National League for Nursing.

Wilson, S. Coenen, A. Doorenbos, A. (2006). Dignified dying as a nursing phenomenon in the United States. *Journal of Hospice and Palliative Care Nursing, 8* (1), 34-41.

World Health Organization (2002) *National Cancer Control Programs: Policies and Managerial Guidelines,* (2nd ed). WHO: Geneva.

Young, C. & Koopsen, C. (2011). *Spirituality health and healing: An integrative approach* (2nd ed.). Toronto: Jones and Bartlett.

Zaza, C., Sellick S., & Hillier, L. (2005). Coping with cancer: What do cancer patients Do? *Journal of Psychosocial Oncology, 23* (1), 55-73

Zerwekh, J.V. (2006). *Nursing care at the end of life: Palliative care for patients and families.* Philadelphia: F.A. Davis Company.

Appendix A

Demographic Questionnaire

Code #_____   Age____   Marital Status_____

Highest Level of Education

    __ Diploma   ___ MSN

    __ ADN   ___ PhD

    __ BSN   ___ Degrees other than nursing

Other significant training or certification_____

Years of experience in nursing_____

Years of experience in palliative care_____

Household Income in dollars per year

Less than 10,000 _____   10,001 – 20,000 _____ 20,001 - 30,000 _____

30,001 – 40,000 _____   40,001 – 50,000 _____ 50,001 – 60,000 _____

60,001 – 70, 000 _____   70,001 – 80,000 _____ 80,001 – 90,000 _____

90,001 – 100, 000_____   Over 100, 000 _____

Religious Preference_____   How often do you attend church? ____

How often do you engage in spiritual practices or rituals? _____

Appendix B

Historical and Self Awareness Interview Guide #1

Tell me about yourself and your upbringing?

What was your spiritual or religious upbringing? Where there any turning

points for you? What experiences have challenged your views?

What influences or experiences of your upbringing assist you with spiritual

caring?

As a nursing student did you care for a dying patient? What was that experience

like? Did anything help or hinder your care giving? What were your concerns?

Priorities?

Tell me about any experiences you have had with friends or family   members

who were dying? What was that like?

How would you describe care of the spirit for yourself and others?

Tell me about your understanding of things that are important for you

 when providing spiritual care at this time?

How has your nursing education and career assisted you with providing

spiritual care?

How have other life experiences contributed to your providing spiritual care?

What kind of education or training have you had in the area of spiritual caring?

Appendix C

Nursing Process Interview Guide #2

Tell me what spiritual care for dying patients and their families encompasses?

Tell me about your practice of spiritual care for patients and families at end of life?

How do you recognize a patient or family's spiritual needs?

What aspects of your role as a palliative care nurse attends to the spiritual needs of patients and their families?

How do you evaluate the spiritual care you provide?

Can you describe any challenges you have in providing spiritual care?

Is there anything else you would like to add?

Appendix D

Expertise in Practice Interview Guide #3

The following questions and probes are adapted and extracted from Benner et

al. (2009, p. 465-468). They described the extent of expertise in nine separate

dimensions with probes that help to get at more descriptive data. Once a

meaningful narrative emerges probes were utilized to get at dimensions of the

story that reveal expertise in practice.

Dimension 1 Differences in kinds of unstructured problem identification.

Content selected for examples of optimal and suboptimal performances

Question1: Could you tell me about a time that was very meaningful and went

for you while caring for patient or family members spiritual needs at end of

life?

Question 2: Could you tell me about a time that was difficult in caring for

patient or family members spiritual needs at end of life?

Dimension 2 Awareness and use of strategies to handle" changing relevance"

as the problem unfolds.

Data source: Narrative account plus the following probes.

1. Through the course of this incident, did you come to see the situation
   in a different way?
2. What were your priorities during the situation?
3. Did your priorities change during the clinical episode? If so, how?
4. Did your focus on major concerns change over the course of this
   clinical situation? How?

5. Can you think of any generalizations you were making from your prior work with patients that you used with this particular problem?

Dimension 3 Expectations and sets evident in clinical performance.

Data sources: Narrative accounts and participant observation with the following probes:

1. What were your major expectations in this situation?
2. Where do you think those expectations came?
3. Where you at all taken by surprise in this situation?
4. What were you watching out for in this situation?
5. How have your perspectives changed since coming to this area of nursing?

Dimension 4: The rules, principles, and maxims at different levels of skill acquisition.

Data sources: Narrative accounts, participant observation and the following probes?

1. Would you have done _____ with any palliative care patient?
2. Can you identify any rules or guiding principles that informed or guided your behavior in the situation you described?
3. What guidelines would you give another nurse for handling the same kind of situation?
4. How would your advice change if you were talking to a beginner?
5. What were the dos and don'ts that you were concerned about in this particular case?

Dimension 5: The use of relevant clinical population comparisons that demonstrate the ability to recognize similarity in the particular case with an appropriate group of similar patient problems.

Data sources: Narrative accounts, participant observation and the following probes?

1. Had you worked with patients that had similar problems before?
2. Did this case trigger any memories of other cases?
3. What led you to identify_____ as a problem?
4. Did you draw from any readings, lectures, or other information when dealing with this problem?

Dimension 6: The use of analytic verses instance oriented strategies.

Data sources: Narrative accounts; fund of memorable paradigm cases; and questions on dimensions 4 and 5.

1. In looking at what you did in this situation, would you say that you were guided more by past experience with similar cases or by what you have learned in books? Lectures?
2. Did you reason out what to do in this case?

Dimension7: The role of hunches or understanding without obvious rational explanation in problem identification and intervention.

Data sources: Narrative accounts and participant observation, plus the following interview probes?

1. Did you do anything based on a hunch?
2. What were you hunches in this situation?
3. What do you think your hunch is based on?
4. Do you have any emotional or physical sensations associated with your hunch?
5. How certain did you feel about your hunch?
6. Do you hunches in your practice? Around what issues?
7. Any past hunches stand out in your mind?

Dimension 8: Differences in the fund of memorable "paradigm cases" cases that stand out as teaching a new clinical understanding or recognition ability.

Data sources: Narrative account

Dimension 9: Characterization of the nature of the task along intuitive dimensions.

Data sources: Narrative accounts and the following probes?

1. Can you think of things in this situation or others that gave you a warning signal of patient or family qualitative changes or readiness to learn or grow?

Appendix E

<u>Reflexive Journal Form</u>

<u>Subject pseudonym</u>:

<u>Date/Time/Location of interview</u>:

<u>Room Environment</u>:

<u>Subject affect at beginning of interview</u>:

<u>Subject affect during interview</u>:

<u>Subject affect at completion of interview</u>:

<u>Notable events observed during interview</u>:

<u>Interviewer feelings before interview</u>:

<u>Interviewer feelings during interview</u>:

<u>Interviewer feelings at end of interview</u>:

<u>Additional comments</u>:

Appendix F

Participant Pseudo Name /Age	Race Marital Status Household Income/year	Education Certifications Practice Setting	Years in Nursing/Years in Palliative Care	Faith Tradition/Church Attendance & Spiritual practice
Lucy/52	Caucasian Divorced 60,0001-70,000	BSN HPCN Suburban	32 10	Methodist Regularly Weekly
Melissa/54	Caucasian Married Declined	BSN Pain Cert. Urban	34 3	Catholic Weekly Daily
Donna/ 51	Caucasian Married 80,001-90,000	AND HPCN/ Pain Suburban	30 7	Christian Rarely Daily
Bev/57	Caucasian Married Over 100,000	BSN/MA CHPN Suburban	35 7	Catholic Weekly Daily
Jane/ 49	Caucasian Married 70,001-80,000	MSN CHPN Suburban	28 6	Catholic Weekly Daily
Sophia/57	African Am. Married Over 100,000	MSN OCN, ACHPM, APN Urban	17 4	Baptist 1-2 times/month Daily
Barb/57	Caucasian Married 70,001-80,000	BSN OCN, Healing Touch Rural	30 2 1 year of hospice ten yrs ago	Unitarian 2-3 times/month Weekly
Betty/55	Caucasian Married Over 100,00	BSN, CHPN Rural	37 12	Lutheran Biweekly Weekly
Vicki/56	Caucasian Married 70,001-80,000	BSN CHPN Rural	35 6	Methodist Weekly Daily
Cindy/ 46	Caucasian Married Over 100,00	AND CHPN Rural	25 6.5	Lutheran Biweekly Weekly

Appendix G

Participant Recruitment Form

I am writing to let you know about a research project being done this spring. We want to learn more about the cultivation and practice of spiritual care expertise in an inpatient palliative care setting for patients and families at end of life. We use information from these research studies to help us find ways to improve nursing care.

Jean Bachman RN, PhD has been a nurse, educator and researcher for over 30 years and will be working with Gail Pittroff RN, PhD (c) who is an instructor at the Goldfarb School of Nursing at Barnes Jewish College and a PhD candidate at the University of Missouri St. Louis. Jean is Gail's doctoral chairperson at the University of Missouri St. Louis. Gail's aim is to explore what it is like for inpatient palliative care nurse specialists to provide spiritual care for patients and families at end of life in an inpatient setting.

Participating in this study will require approximately 3 hours of your time. Your participation will consist of 2 interviews about 1.5 hours long, which will be audio-taped. During these interviews we would like you to tell us what your education, practice and lived experience is like while providing care for patients and families at end of life in an inpatient setting. We estimate that 12 individuals will be participating in this study. All data will be coded such that you will not be identified in any manner.

If you would like to know more about this research study, we need your permission for Gail Pittroff to contact you. Your participation in this study is completely voluntary. Participation in this study may not benefit you directly, but what we learn from these kinds of studies is valuable to the care we provide. Please contact Gail Pittroff RN, PhDc at (314) 401-5112 or Jean Bachman RN, PhD at (314) 516-6075.

If you are interested in participating in this study or learning more about this study please indicate by checking the "yes" box below and return this form in the envelope provided. You may also contact Gail Pittroff at (314) 401-5112.

□ Yes-indicates your permission to have Gail Pittroff contact you.

□ No-indicates you are not interested in participated in this study.

If yes, please indicate the best way to contact you_____ (phone or email)

Respectfully,

Gail E. Pittroff RN, PhDc

Appendix H

College of Nursing

One University Boulevard

St. Louis, Missouri 63121-4499

Telephone: 314-516-6075

Fax: 314-516-7082

E-mail: bachmanj@umsl.edu

Informed Consent for Participation in Research Activities
The Cultivation and Practice of Spiritual Care Expertise in an Inpatient Palliative
Care Setting

Participant_____   HSC Approval Number <u>100128P</u>

<u>Principal Investigator Gail Pittroff</u>   <u>PI's Phone Number 314-401-5112</u>

<u>Why am I being asked to participate?</u>

You are invited to participate in a research study about the cultivation and practice of spiritual care giving for inpatient palliative care patients and families who are near end of life conducted by Gail Pittroff through the nursing department at the University of Missouri-St. Louis. You have been asked to participate in the research because you have been identified as a palliative care provider in the Midwest area and may be eligible to participate. We ask that you read this form and ask any questions you may have before agreeing to be in the research. Your participation in this research is voluntary. Your decision whether to participate will not affect your current or future relations with the University or Goldfarb School of Nursing. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

<u>What is the purpose of this research?</u>

The purpose of this study is to better understand how inpatient palliative care nurse consultants provide spiritual care at end of life and how they acquired these skills. Nurses will be asked to describe their experiences of spiritual care giving in an inpatient palliative setting. The specific aims of the study are as follows:

1. Examine the spiritual care practices of nurses providing palliative care for dying patients and their families in an inpatient setting.

2. Discover how palliative care nurses recognize a patient or family's spiritual care needs.

3. Discover the personhood of the nurses providing spiritual care for dying patients and their families.

4. Examine how nurses acquire the skills to provide spiritual care and how those skills develop.

What procedures are involved?

If you agree to participate in this research, you can expect:

A meeting and interview with the primary investigator at a mutually agreed upon location on two separate occasions about four weeks apart for no longer than one and one-half hours.

A third meeting may be arranged if necessary to validate findings.

Approximately 10-15 people may be involved in this research at the University of Missouri-St. Louis.

What are the potential risks and discomforts?

There are certain risks and discomforts that may be associated with this research. They include:

Emotional discomfort associated with describing patient and family interactions that were not favorable. Grief triggered from remembering and describing caring for dying patients. Should you experience discomfort the interview will stop and only resume if and when you choose? You may withdraw from this study at any time.

Are there benefits to taking part in the research?

The benefits to taking part in this research include advancing nursing science, education and research. Other benefits include giving voice to the important work of spiritual care that you and others provide for patients and families at end of life.

What about privacy and confidentiality?

The only people who will know that you are a research subject are members of the research team. No information about you will be provided during the research, will be disclosed to others without your written permission, except:

- if necessary to protect your rights or welfare (for example, if you are injured and need emergency care or when the University of Missouri-St Louis Institutional Review Board monitors the research or consent process); or
- if required by law.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. If photographs, videos or audiotape recordings of you will be used for educational purposes, your identity will be protected or disguised. Any information that is obtained in connection with this study, and that can be identified with you, will remain confidential and will be disclosed only with your permission or as required by law.

The interviews will be audio taped and transcribed with a pseudo name. The interview transcripts and demographic data survey sheet will be coded and the master list will be locked in a drawer in my office at Goldfarb School of Nursing. Once transcribed you may have the tape if you desire or it will be destroyed.

The research team will use and share your information until the tape is transcribed. At that point, the investigator will remove the identifiers from your information, making it impossible to link you to the study.

What are the costs for participating in this research?

The only cost would be gasoline to drive to a mutually agreed upon location for the interview.

Will I be paid for my participation in this research?

Upon completion of the second interview and validation of findings the participant will be given a fifty dollar gift card to offset costs associated with driving. Should the participant withdraw they will forfeit this monetary offering if no interviews were completed or be offered a prorated gift card amount of 25.00 if only one interview was completed.

Can I withdraw or be removed from the study?

You can choose whether to be in this study. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You also may refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so. If you decide to end your participation in the study, please complete

the withdrawal letter. http://www.umsl.edu/services/ora/assets/WithdrawalLetter.doc, or you may request that the Investigator send you a copy of the letter.

The primary investigator may also withdraw you from the study for reasons that include psychological or emotional instability.

Who should I contact if I have questions?

The researcher conducting this study is Gail Pittroff. You may ask any questions you have now. If you have questions later, you may contact the researcher at 314-401-5112.

What are my rights as a research subject?

If you have any questions about your rights as a research subject, you may call the Chairperson of the Institutional Review Board at (314) 516-5897.

Remember: Your participation in this research is voluntary. Your decision whether to participate will not affect your current or future relations with the University or Goldfarb School of Nursing. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

You will be given a copy of this form for your information and to keep for your records.

I have read the above statement and have been able to express my concerns, to which the investigator has responded satisfactorily. I believe I understand the purpose of the study, as well as the potential benefits and risks that are involved. I authorize the use of my PHI and give my permission to participate in the research described above.

_____

Participant's Signature   Date   Participant's Printed Name

_____

Researcher's Signature   Date

Appendix I

Participant Validation Document

Hello Everyone,

This is a standard document that I am sending out to the participants of my study. First of all I want to thank you all for your time and heartfelt responses. It has been a privilege to work with you and to attempt to illuminate the important role you have. I have plenty of data to proceed with this project.

Interpretive qualitative research involves the researcher pulling out exemplars of dialogue that reflect their study aims. These exemplars are also set in dialogue with existing literature and new or illuminating concepts are also presented. My aims in the study included:

5. Examine the spiritual care practices of nurses providing palliative care for dying patients and their families in an inpatient setting.

6. Discover how palliative care nurses recognize a patient or family's spiritual care needs.

7. Discover the "personhood" of the nurses providing spiritual care for dying patients and their families.

8. Examine how nurses acquire the skills to provide spiritual care and how those skills develop.

If you recall, I used the Benner model of expertise interview guide to uncover how nurses represent expertise in practice. Benner's original work on skill acquisition was also formulated using interpretive phenomenology. From her research she wrote numerous articles and books to name a few included, *Novice to Expert and Expert Practice: Caring, Clinical Judgment and Ethics.* My study is focused on the expert level of practice that Benner describes but limited to spiritual caring in an inpatient palliative care setting. However, the nurses Benner studied were intensive care nurses and reflected a critical care context. I utilized the same methodology to see how spiritual caring at end of life fit or did not fit with her model. According to Benner, expertise reflects 5 domains that include; **clinical grasp and response based practice, embodied know how, seeing the big picture, seeing the unexpected and agency.**

Everyone in this study spoke to these domains within the context of our interviews. I had no difficulty locating these domains in the narratives that you provided. I also want to say that isolating dialogue that fits these domains is not simple. I found that

many of these domains overlap and are not mutually exclusive. For instance, when a nurse responds to ineffective coping by patients or family at end of life one could argue that the nurse represents all the domains. Confusing right? Keep in mind these domains represent an idea or phenomena of expertise that can be analyzed separately for study but in practice nurses function at this level holistically with integration. I plan to illuminate this when I discuss expertise in Chapter 4 of the dissertation and present a paradigm case. Just for your information, Chapter 1 is background and significance for the study. Chapter 2 is review of the literature and Chapter 3 is methodology. I will provide you all an electronic copy of the entire work upon completion. This hopefully will come near Christmas and hopefully will serve as a Christmas present for you which in turn reflect the gifts you share in practice as palliative care professionals.

Nearly all of what I heard in these interviews fit the expert domains described by Benner in one way or another. I did notice though that Benner, when speaking about the expert in general states that "the expert nurse does not rely on rules or maxims and uses assessment language at a minimum." Remember however, she studied intensive care nurses and they revealed expert knowing on an intuitive level. They said things like "I just knew he was crashing" "I could tell things had changed" etc. These exemplars that Benner selected to illuminate intuition of the expert were based on tacit signs that only an experienced nurse speaks about or can pick up on. Many of you spoke to this in the way you read a spiritual situation, the tone and mood of your patients and families, the tensions in the room are palpable for many of you. You can tell intuitively for instance, the family needs more time to process and you respond to this cue on behalf of their spiritual well being. You rely on your intuition for decision making and that fits with her model of expertise. Many of you also spoke to a heightened sense of assessment. In other words, in terms of spiritual caring it is profoundly important to assess a patient's and their family's spiritual needs because it is so highly individualized and has multiple meanings for people.

My job as a researcher was to select from the interviews a paradigm case on expertise. Unfortunately that involves only one nurse's transcript, in dialogue with the literature and my interpretations. This will be illuminated in Chapter 4 of the dissertation. Please understand that you all represented expertise in multiple ways. I plan to represent all of your voices which will be represented in the themes section in chapter 5 of the dissertation, a discussion on personhood and practice. The Theme of Chapter 5 will be entitled *The Humbled Expert.* I will close with implications for education, research and practice etc. I am currently in the process of drafting chapters 4-5.

The *Humbled Expert* theme will take into account the personhood and practice of the palliative care nurse consultant. I came up with this concept and theme because it is paradoxical. Not many people think of an expert as humble. Yet in this context, humility is of the essence. Many of you in your own personal and professional woundedness and or losses have transcended your strife and offer an alternative to suffering. You know how it feels to be slighted, some through personal illness and many through family illness and death. Yet you respond to people undergoing tragedy, loss and fear of the unknown with empathy and courage to offer what I call metaphorically "bread instead of crumbs." You are present and steadfast never wavering from support and that is not simple given the nature of loss and family dynamics that unfold in the process of loss. You recognize what you can mend as well as the obstacles you cannot surmount, accepting your limitations. You also know when to refer and when you are beyond the scope of your expertise. Yet in your service to others you describe a mutuality of care. In other words you get as much as you give and have described your role as one of joy, privilege and honor. You manifest the desire of a good and peaceful death on all levels including the physical, psychosocial and spiritual realms. You recognize the potential for dysfunctional grief that stems from guilt, shame, lack of reconciled relationship etc. and work to minimize this for families undergoing loss.

Your nursing practice involves developing rapport and trust with patients and family which you usually have with ease. You display all the elements of spiritual caring that are already well discussed in the literature.

What is not standard in the literature which I believe is paramount in your role and often taken for granted in this culture and yes even in nursing, is humility. Your transcripts convey this clearly to me. Nursing and especially palliative care nursing has enlarged your perception of life and enabled you to engage and respond to suffering with more options. Beverly (pseudo name) said it all, "There, but for the grace of God go I." You all have the gift of humility. Martin Buber spoke of the *I and Thou* relationship and your stance with patients and families reflect the essence of a subject to subject verse subject to object way of relating. Palliative care nurses articulate the awareness of the fragility of life, the essence of spirituality and whole persons, the experience of suffering and the deep human need for connectedness. They respond with deep advocacy illuminated in multiple ways for their patients and families.

Given that "humble" stance you rely on intuition as well as careful assessment to meet the spiritual care needs of your patients and family. You find out what is meaningful and bring that into the care of your clients. Another unique finding that I do not see in the literature is your ability to assess your patient's and family's belief

system, and unite this with decision making regarding goals of care and treatment at end of life. This skill enables many of your patients and families to engage the reality of what is happening and creates an environment for spiritual harmony at end of life resulting in a dignified, peaceful death. Some of you also spoke of person's belief systems interfering with a peaceful death and how you struggle with that personally, yet you support their beliefs and desires. You have come to terms with "otherness" ultimately knowing this is your role and you help other staff to see this as well.

Your passion for this work stems from a deep vocational calling. Many of you described feeling "sent" in a very real missional sense. Your experiences in life and nursing practice both negative and positive inform your work. However, none of you came to any of your spiritual care knowing through formal nursing education. What little instruction you had, was just the tip of the iceberg. Most of you have attained additional education either formally or through continuing education. You have also modeled spiritual caring by watching others do it and of course through trial and error. Your ability to provide this kind of care has evolved through life's journey and your own desire to manifest what you believe people want and need. You place yourself in the shoes of your patients and families and your level of involvement is dictated based on their needs representing effective agency in practice.

I plan to illuminate the humbled expert along with three sub themes: the I and thou relational stance, enlisting other experts and new found attitudes, behaviors and communal skills or ABC's of spiritual care. The attitude I will illuminate that is underdeveloped in the current literature is openness. The behaviors I will illuminate are careful assessment and utilization of patient and family belief systems for harmony with decision making. The communal skill I plan to illuminate which is also under represented in the current literature is your ability to engage and empower others.

This document is being sent to you to affirm from you that you are in agreement with the overarching themes I have found in this study as reflecting spiritual care at end of life in an inpatient palliative care setting. Keep in mind not every participant spoke to every theme I plan to develop and illuminate 100% of the time. This is not necessary for interpretive research. What I am asking from you is to look over these concepts, ideas and themes. Please let me know if you if you see yourself and your practice as fitting with the themes in general. Do you see yourself fitting under the theme in one way or another as a *Humbled Expert*? Do you view your practice as open? Do you assess carefully and when appropriate unite the beliefs and values of patients and families with decision making? Do you empower others in your care? Do you respond to patients and families that may be radically different from your own understandings and beliefs with the same spiritual support, advocacy and care you

provide those similar to yourself? This gives you the opportunity to let me know if you don't feel that your interviews reflected the themes and therefore I would not select any of the dialogue in your transcript when writing about them. Please e-mail a **yes** I agree statement. Or a **no** we need to talk message which then I will contact you by phone. As always feel free to call me at 314-846-7905 or 314-401-5112 with questions or concerns.

In closing, I just want to add that reading your transcripts are like listening to a choir, you can hear one unique voice from time to time yet it is in harmony with the others. Together there is strong unison of spiritual caring that rings loudly and beautifully. It makes me cry, and I am so very grateful for the gift of your song and your spirit.

Thank you,

Gail Pittroff, PhDc, RN