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UNDERSTANDING NURSES' EXPERIENCES OF PROVIDING END-OF-LIFE CARE IN  
THE UNITED STATES HOSPITAL SETTING

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy in Nursing at Virginia Commonwealth University.

By

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Virginia Commonwealth University  
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## Abstract

### UNDERSTANDING NURSES' EXPERIENCES OF PROVIDING END-OF-LIFE CARE IN THE UNITED STATES HOSPITAL SETTING

By: Susan C. Johnson, PhD, RN

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing at Virginia Commonwealth University.

Virginia Commonwealth University, 2010.

Major Director: D. Patricia Gray, PhD, RN  
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Nurses perform a vital role in the care of dying patients and their families. Hence, experiences of nurses are a meaningful source from which to advance holistic end-of-life care. In this study, a hermeneutic phenomenological perspective was used to explore the phenomenon of end-of-life nursing care. Details derived from a scientific exploration into the experiences of 13 registered nurses who provided care for patients and families at end-of-life in the inpatient hospital setting offer understandings regarding this important phenomenon. The hermeneutic phenomenological methods of Max van Manen guided data collection and analysis. Three main themes described the participants' experience of nursing care at end-of-life: "Confronting Challenges," "Coming to Understand End-of-Life Care," and "Transforming the Understanding of End-of-Life Care into Nursing Practice." Recommendations for nursing education, practice, and research were derived.

## Chapter 1 Introduction

Within the American healthcare system there is a growing concern among professional care providers regarding end-of-life care. The 2008 United States (US) Census Bureau Report<sup>1</sup> projects that 70-million people will be over the age of 65 years by the year 2030. This age-group is estimated to expand to 88.5-million in 2050. Greater than 70% of these individuals are expected to expire from chronic illnesses or terminal conditions within institutionalized settings, most notably the acute care hospital.<sup>2</sup> However, the experiences of dying and death challenge the technological and curative culture of most American hospitals. Hence this environment has increasingly become an important focus for efforts to improve quality at end-of-life in the US healthcare system.<sup>2,3</sup> Because professional nursing is a vital component of care for hospitalized patients and their families, regardless of care setting or stage of illness, nurses in all inpatient clinical settings have a pivotal role in ensuring quality outcomes at end-of-life.

This growing emphasis on end-of-life care requires that hospital nurses develop profound knowledge and understanding of dying and death. Excellence in clinical practice necessitates that professional nurses possess the expertise to competently and compassionately respond to a range of complex and inter-related patient and family needs at end-of-life – physiological, emotional, social, cultural, and spiritual. Thus the vitality of nursing's role during dying and death depends not only upon the acquisition of knowledge and understanding but also the transformation of this knowledge into meaningful, holistic practice.

A presentation describing the influence of hermeneutic-phenomenological knowledge on the development of holistic, integrated nursing care is presented in Chapter 2. In this chapter the historical context for current end-of-life and palliative care practices within western society is

examined. The perspectives of terminally-ill patients within the context of the family highlight whole-person dimensions of the human experience for both living and dying individuals. Through the lens of these compelling perspectives, insights into the value of hermeneutic phenomenology are revealed. The chapter concludes with recommendations for authentic end-of-life nursing praxis, rooted in the hermeneutic-phenomenological tradition and derived from the substantive evidence of patient and family perspectives at end-of-life.

As nursing knowledge regarding dying and death accumulates, nurses will grow in their ability to significantly influence the quality of end-of-life care. Previous researchers and clinicians contended that the systematic exploration into actual experiences and reflections of nurses who care for terminally-ill persons could provide a deeper understanding of end-of-life care and its complexities.<sup>4-6</sup> The works of these scholars suggested that the findings of such investigations would be reliable sources from which to build support for continued advancement of compassionate, holistic end-of-life care. Despite these scholarly suggestions, research regarding the experiences of nurses who provide care for terminally-ill patients and their families in the hospital setting has remained limited. Most recent research (2005-2010)<sup>7-14</sup> has focused on particular facets of end-of-life nursing care such as education or problematic care processes. However, few of these studies have addressed aspects of hermeneutic phenomenology and the personal accounts of professional nurses within the inpatient hospital setting have not often been recorded or examined.

Chapter 3 provides details derived from scientific exploration into the first-hand experiences of registered nurses who provide care for dying patients and their families in the hospital setting. Specifically, the focus of this inquiry addressed the following research question: “Among nurses who provide end-of-life care for adults in inpatient hospital settings in the United

States, what are their understandings of those experiences?” Hermeneutic phenomenology was utilized to answer the research question because this approach facilitates greater understanding of human experiences and offers a foundation for scientific inquiry regarding nursing phenomena such as care at the time of dying and death.<sup>15-17</sup> Research methods outlined by van Manen<sup>17</sup> (1990) guided the conduct of the study throughout all phases of investigation.

13 registered nurses who met study inclusion criteria consented to participate and were enrolled in this study regarding end-of-life nursing care. During semi-structured face-to-face interviews, the investigator asked individual participants to share thoughts, feelings, reflections and meaningful experiences in providing end-of-life care for patients or their families. Interviews which lasted 60-90 minutes in duration were audio-taped. The audio recordings of participant interviews were transcribed into text and the transcribed text served as the data for analysis, along with field notes and the investigator’s personal reflection journal. An iterative process of data collection and analysis was employed. The investigator used the criteria delineated by Sandelowski<sup>18</sup> to facilitate scientific rigor of both study processes and study outcomes.

As data were analyzed the investigator considered the parts and whole of the transcripts as a hermeneutic spiral of understanding.<sup>15-17</sup> This dynamic and iterative process guided the discernment of themes and sub-themes that depicted the experiences of nurses providing care at end-of-life in the inpatient hospital setting. Three distinct yet interwoven themes described these experiences across all clinical care venues: “Confronting Challenges,” “Coming to Understand End-of-Life Care,” and “Transforming the Understanding of End-of-Life Care into Nursing Practice.” The narratives of the nurse participants underscored that genuine quality resulted from the integration of scientific knowledge and skill in conjunction with a deep understanding of human dimensions of care.

The findings gained from exploring end-of-life care in the inpatient hospital setting from the perspective of registered nurses contribute to both patient care and professional development. First of all, the study provides greater understanding of important insights that contribute to quality patient care outcomes. These same insights offer support to professional nurses in their future development of holistic end-of-life caring practices.

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Chapter 2  
(Manuscript 1)

Hermeneutic Understanding:  
Essential for Authentic End-of-Life Patient-Centered Nursing Praxis

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## **Hermeneutic Understanding:**

### **Essential for Authentic End-of-Life Patient-Centered Nursing Praxis**

The subject of death and dying occupies both the attention and the inquiring minds of all reflective human beings because we and those we love will undoubtedly die.<sup>1</sup> This human experience is at once unique and paramount, complete and final. Because dying and death involve the whole of one's being, professional attention to human wholeness is vitally important at the time of dying – perhaps more vital than at any other time in the human lifespan.

Projections in the 2008 United States (US) Census Bureau Report<sup>2</sup> indicate that by the year 2030, 70-million people will be over the age of 65 years. This age-group is projected to increase to 88.5-million in 2050. Over 70% of these individuals are expected to die in institutionalized settings, such as hospitals and nursing homes.<sup>3</sup> The majority will die from chronic illnesses and terminal conditions with nurses playing a vital role in their care and that of their families. These facts and statistics suggest that contemporary inquiry should not simply address the *what*, *when* or *where* of death. Equally if not more important is the question of *how* people will experience their dying. As answers are sought, the significance of nursing's role will continue to intensify. Given the number of individuals expected to die in institutionalized settings and the importance of nursing care in those settings, the answer to the question of *how* depends largely upon nurses acquiring a more profound knowledge of the dying experience. Attention to the dimensions of human wholeness during dying and death depends upon nurses transforming this knowledge into meaningful action.

Within the discipline of nursing, the transformation of knowledge into meaningful action is known as praxis, an unbroken unity of art, science, and practice.<sup>4</sup> Nursing praxis is fostered by the cultivation of hermeneutic understanding. Because the ontology and epistemology of

hermeneutics emphasizes human meaning and value, the integration of practices that embrace human dignity and human wholeness becomes possible. This emphasis on human dimensions of care complements scientific knowledge and technical skill, thus making nursing care complete.

This paper offers a vision for authentic patient-centered nursing praxis at end-of-life. The historical context for current end-of-life and palliative care practices within western society is reviewed. The perspectives of terminally-ill patients within the context of family highlight the need for nursing focus on the wholeness of the human experience of both living and dying. The value of human dignity and human wholeness are central features of the ontological and epistemological foundations of hermeneutic phenomenology. Recommendations for authentic end-of-life nursing praxis are provided, rooted in the hermeneutic tradition and derived from the substantive evidence of patient and family perspectives at the end-of-life.

### **End-of Life and Palliative Care**

Historical, cultural, and societal trends are among the most important factors influencing human experiences such as dying and death. Bookbinder, Kiss and Matzo<sup>5</sup> examined trends during the twentieth century and noted the implications for end-of-life care in contemporary western society. For example, in 1900 life expectancy was less than 50 years of age for most people in America, and they generally died in their homes surrounded by loved-ones. During the twentieth century multiple advancements in knowledge and technology occurred that resulted in far-reaching modifications in health care. These changes contributed to trends such as an increase in the human lifespan, an increase in the number of individuals living with chronic and terminal diseases, and a widespread shift to institutionalized care. Health care providers and citizens alike embraced an emphasis on science and technology in the institutionalized healthcare system. As an unforeseen consequence, the dimensions of care that had previously been

supported by family and loved ones in the domestic setting were frequently fragmented or altogether neglected in the institutional setting.

Contemporary models for end-of-life care evolved, in part, from recognition of this inattention to the human dimensions of care in the institutionalized healthcare environment. Identification of other major deficiencies and inefficiencies in end-of-life care also influenced the contemporary palliative care movement.<sup>6</sup> In recent years, substantial resources have been expended by many professional disciplines to stimulate constructive health-system change for end-of-life care.

Contemporary models for optimal end-of-life care integrate both hospice and palliative care services.<sup>7</sup> Within the contemporary view, patients may include persons with progressive or incurable illnesses such as end-stage organ disease, dementia, and neurodegenerative disease in addition to persons with cancer and AIDS.<sup>8(p xix)</sup> Palliative care is intended to encourage disease-modifying and supportive therapies to alleviate physical symptoms while also addressing psychosocial, cultural, and spiritual needs of patients and families who are experiencing life-threatening progressive illness.<sup>9</sup> The contemporary goal of palliative care in western society is to enhance quality of life for the patient and family through a) relief of suffering along the illness and dying trajectory and b) provision of support during patient death and family bereavement.<sup>7</sup> Consistent with the goals of palliative care, comprehensive interdisciplinary standards have been developed to guide quality improvement efforts in hospice, palliative care, and other clinical settings in the United States.<sup>9,10</sup> Table 1.0 summarizes key societal trends, landmark publications and significant historical epochs in palliative care nursing.<sup>5,7,11</sup>

In spite of these and other significant advancements in the field of palliative care, the need persists for ongoing strategic focus on end-of-life care. Indeed, the National Institute of

Nursing Research (NINR)<sup>11</sup> recently reaffirmed the importance for knowledge development and ongoing improvement in quality of life for dying patients and their caregivers. Future efforts to improve end-of-life care take place against the backdrop of lived experiences of patients within the context of family; this evidence is reviewed in the following section. The lived experience of dying continues to challenge health care providers to find approaches to care focused on human wholeness and dignity.<sup>3</sup>

### **End-of-Life: Patient and Family Perspectives**

Dying and death are deeply personal for patients and their loved ones. Individuals encountering this intimate experience have potential to contribute a genuinely unique viewpoint. Contemporary standards of palliative care have also emphasized the importance of considering patients' perspectives. Thus, exploration into the experiential nature of dying gives "voice" to what may be *most* important to patients and their families and thereby supports ongoing efforts to develop knowledge and improve care that deeply recognizes the value of human wholeness and dignity.<sup>3</sup>

Since the advent of the contemporary palliative care movement numerous research studies have been conducted. A number of these studies have provided information regarding perspectives and experiences of patients within the context of family.<sup>12-32</sup> Within the past decade (1999-2009) patient-focused studies published in the English language reflected consistent and complementary findings that clearly corroborate the necessity for attention to human dimensions of care. An analysis of selected research summarized in Table 2 leads to four main conclusions.<sup>12-32</sup>

First, researchers documented that multiple inter-related challenges confronted participants – both patients and families at end-of-life.<sup>13,16,19,22,25,31</sup> For example, challenges

identified in one study included pain and symptom management, the need to strengthen relationships, a need for sense of control, relieving sense of burden, and dying in peace.<sup>12</sup> In yet another study a combination of physical challenges, functional limitations, and existential concerns confronted patients at end of life.<sup>31</sup> Patient and family challenges were most often interconnected and could not be considered singularly. Secondly, end-of-life priorities of patient and family-member participants oftentimes differed from those of participants who were professional caregivers.<sup>12,14,17,28,30</sup> Professional care providers commonly focused on disease management and symptom control, while patients' priorities tended to be psychosocial, spiritual, and existential. Thirdly, a diversity of experiences and varying perspectives regarding priorities in life and death were often evident among terminally-ill participants.<sup>15,19,20,23,32</sup> This diversity was influenced by contextual and relational aspects of life. For example, Vig and Pearlman<sup>20</sup> found that terminally-ill study participants did not have a uniform view regarding "good" death; their past experiences with death influenced their views. Likewise, Heyland and colleagues<sup>23</sup> found that demographic factors such as social support influenced hospitalized participants' perceptions regarding priorities at end-of-life. Lastly, study participants emphasized a need for emotional support and a compassionate approach. In several studies patients and families conveyed the need to be seen, have individual lived experiences listened to, and to be cared for in their unique wholeness.<sup>12,14,15,18</sup>

Throughout these studies, there were persistent reminders of the importance of existential considerations such as human relationships, dignity, and meaning to those who were dying. These reminders often took the form of expressed existential suffering by the terminally-ill participants such as feelings of burden, distress, or abandonment and loss of dignity.<sup>16,21,24,26,27,31</sup>

Suffering resulted when whole-patient end-of-life needs were not identified or remained unaddressed.<sup>26</sup>

The primacy of human dignity and the confirmation that genuine quality of life emanates not only from physical but also from psychosocial, cultural, spiritual, and existential dimensions are among the most significant end-of-life recommendations gleaned from this research involving patients and their families. When the implications of recent research studies are considered – not only individually, but collectively – the answer to the inquiry of how persons will experience their dying in the future is inextricably linked to knowledge expression and expansion that takes human wholeness into account. More importantly, findings of recent research strongly suggest that when professional care providers place *fundamental* priority on human dimensions of care, the resultant understanding will provide the clarity for competent and compassionate use of scientific knowledge and skills. In other words, when nurses embrace understanding as a necessary aspect of their professional development, scientific knowledge and technical skill are transformed into praxis. Thus, the cultivation of human understanding has the potential to facilitate authentic *patient-centered* care. Insights derived from hermeneutic phenomenology provide the foundation for such a possibility.

### **Hermeneutic Phenomenology**

Hermeneutic phenomenology is a unique approach for the development of human knowledge and understanding. The underlying ontology of this approach focuses on the value and meaning of the human being. This ontology is consistent with ideals of the interrelatedness of the art, science, and practice of nursing as well as with ideals of human dignity and wholeness.

The evolution of hermeneutic phenomenology was markedly influenced by Martin Heidegger (1929 – 1976) and Hans-Georg Gadamer (1900 – 2002). In the years preceding the

works of these noted philosophers the quest for knowledge, or episteme, resulted in an over-emphasis on scientific objectivism and rationalism. Consequently, the human tradition was suppressed or often wholly neglected.<sup>33</sup> The contributions of Heidegger<sup>34</sup> and Gadamer<sup>35</sup> were revolutionary because exploration of human experience and an understanding of its meaning offered a means to improve the human condition.<sup>33</sup>

The use of hermeneutic inquiry has ancient spiritually-based origins. In the quest for a more complete understanding of life's mysteries, hermeneutics has been used to explore deeper meanings within unfamiliar religious texts and harmonize these meanings with familiar tenets of faith.<sup>36,37</sup> Within the realm of contemporary human-science research hermeneutic phenomenology is both a philosophy of understanding and a method of interpretive inquiry.<sup>38</sup> Although the focus of hermeneutic phenomenology is an exploration of lived human experiences, the underlying intent is similar to ancient hermeneutics – creating a bridge between what is known and familiar with what is unknown.<sup>37</sup> Bridging this gap is transformative since it broadens understanding of the whole of human existence and creates openings for new possibilities of thought and action for addressing complex human needs, such as those at the end of life.<sup>35,36</sup> A brief review of core ontological and epistemological underpinnings of hermeneutic phenomenology reveals significant insights within this tradition that are valuable for authentic patient-centered end-of-life care leading to nursing praxis.

Hermeneutic phenomenology as advocated by Heidegger<sup>34</sup> and Gadamer<sup>35</sup> is grounded in ontological assumptions that are particularly relevant for the human sciences. This philosophical view centers on the human being and from this focus all other ontological assumptions emerge. Leonard<sup>36</sup> has explicated these assumptions: First of all, multiple perspectives of human reality are possible and each perspective is derived from a unique and

individual life-world. The individual's "world" is shaped by virtue of being born at a particular time in history, into a particular culture, and within particular social affiliations. Language and its communication is the exclusive medium in which human meanings, purposes, and values are embedded and disclosed. Therefore, relationships, dialogue, and dialectic are the fundamental ways that human beings link events and experiences of life into inter-related aspects of an ordered and meaningful whole. Furthermore, because the individual's perception of the world is shaped by linguistic skills, socio-cultural practices, and family traditions, his or her reality is always value-laden and context-bound. Thus, language, relationships, and experiences are always inseparable from one's perspective of reality.

When scientific investigation proceeds from the hermeneutic tradition, it is firmly grounded in an epistemology that acknowledges the essence of the human being. Inquiry is intended to interpret meaning of lived human experiences and to provide more complete or alternate understanding of human phenomena.<sup>38</sup> When the hermeneutic perspective is adopted, the investigator acknowledges that understanding of the other ideally begins with a deep awareness of self.<sup>34,35,38</sup> This awareness involves sincere and non-judgmental examination of personal thought, emotions, values, beliefs, biases, strengths and limitations – the totality of one's being. In other words, the investigator recognizes that personal self-understanding represents the initial horizon of understanding from which all interpretation of meaning takes place.<sup>35</sup> This deep exploration into the dimensions of self is accompanied by the investigator's simultaneous recognition that innumerable possibilities evolve from exploring new and different human experiences and relationships. The potential for relationships to expand knowledge regarding human phenomena provides impetus for the investigator to risk engagement with another. Moreover, the investigator recognizes that dialogue and dialectic are indispensable for



cultivating relationships because language is the primary medium in which one's personal perspective is broadened or transformed.<sup>35</sup> By adopting an open, relational, and respectful manner, the investigator assures that each encounter with another human being offers the possibility for expanded understanding regarding dimensions of humanity. Furthermore, by considering each individual within context, the understanding of relational and contextual factors allows for a more appropriate interpretation of what another person values and finds significant in life.<sup>36</sup>

Hermeneutic phenomenology offers a rich and profound view of knowledge and understanding. The hermeneutic tradition recognizes that “no interpretation is ever complete, no explication of meaning is ever final, no insight is beyond challenge.”<sup>39(p viii)</sup> Nevertheless, the human meanings that *are* uncovered always contribute insight into the unknown and unfamiliar, and this understanding beyond the immediate interpretation most often results in “recognitions” that reflect the whole of human life.<sup>35(p63)</sup> The hermeneutic process of understanding is circular, dynamic, and expansive – it has no beginning or end. An infinite number of recognitions or insights are possible. Yet, from the accumulation of these recognitions, a unity of experiences converges and an evolving and living knowledge of the whole is both rendered and sustained.<sup>35</sup>

### **Hermeneutic Understanding and End-of-Life Care**

The phenomenological movement and the works of philosophers such as Heidegger<sup>34</sup> and Gadamer<sup>35</sup> were revolutionary because they legitimized an ontology and epistemology that have provided a foundation for authentic knowledge development regarding the human condition. Similarly, the palliative care movement and the works of palliative care experts have legitimized the value of important skills that support authentic patient-centered end-of-life care. Among the skills endorsed by contemporary palliative care experts and corroborated by findings within patient-centered

research, three are dynamic and inter-related aspects of hermeneutic understanding. These facets of understanding include self-awareness, attention to the life-world of the other, and a deep regard for human relationships. Each of these inter-related aspects of hermeneutic understanding contributes unique insights regarding human wholeness. Thus, exploring the individual and collective relationship of these three aspects to patient-centered end-of-life care will highlight the link to nursing praxis.

### **Self Awareness**

Self-awareness is an ontological endeavor – it is a matter of personal understanding. Palliative care experts have observed that self-awareness is paramount for individuals who wish to provide effective care for dying patients and their families.<sup>40,41</sup> Personal awareness and understanding is a foundation for self-acceptance, self-respect, and love. Paradoxically, these qualities become both boundary and bridge for attention to human dimensions of care at end-of-life.

The professional care provider who embraces self-understanding recognizes personal boundaries and this recognition provides innumerable benefits for end-of-life care. Self-awareness fosters the nurse's capacity for responding to patient-family needs without needlessly imposing personal values, judgments, biases, or false pretenses upon them. Self-awareness also minimizes the risk of inappropriately imposing scientific or technical expertise. For example, a nurse who advocates benefits of invasive treatments may attempt to influence a dying patient who is unable to ingest food or liquids to accept tube feedings even when these are unwanted. Farber & Farber<sup>42(p224)</sup> suggested that inappropriate imposition of scientific expertise, such as in the aforementioned example, can generate intense conflict and cause needless psychosocial suffering especially when "expert certainty" is not aligned with patients' or families' perceptions, values, or goals.

In addition to minimizing risks associated with personal or professional bias, genuine attention to self promotes the nurse's understanding of his or her responses to uncontrollable events and strong human emotions. This understanding is vital at end-of-life lest the caregiver become unnecessarily controlling or risk entangling personal habits or behaviors with circumstances of care.<sup>43</sup> For example, unaddressed personal fears may create the tendency for the nurse to focus on artificial barriers, such as task-work that may be unwarranted, rather than remaining present to the patient during situations imbued with great turmoil. Similarly, unresolved personal needs may cause entanglement in the patient's private affairs. Embracing uncertainty and acknowledging one's personal and professional strengths and limitations allows the nurse to utilize personal energy for addressing pertinent patient and family needs.<sup>42</sup>

Self-awareness facilitates the recognition of a therapeutic boundary of care; it also serves as bridge, or conduit, for patient-centered care. Non-judgmental acceptance of self provides a foundation for acceptance of feelings and behaviors often exhibited by patients or families at end-of-life. Additionally, when the nurse affirms self and cultivates the capacity to speak and act from a place of sincere personal wholeness – body, mind, heart and soul – this act of self-affirmation offers a tacit yet powerful permission for others to speak and act from their own personal truth. As one's self-awareness and self-affirmation matures, an expanding consciousness ensues. This consciousness catalyzes present moment clarity – body and mind are synchronized in the here and now.<sup>41</sup> Synchrony of body and mind in the present moment facilitates attention, and this attention results in a more precise assessment of patient-family needs and circumstances. The nurse is subsequently able to respond to the actuality of *what is* rather than a well-meaning intimation of what *could be* or what *might be*. The resultant authenticity affirms both human dignity and human wholeness.

## **Attention to the Life-World of the Other**

In many research studies dying patients and their families expressed the need for acknowledgement of their humanity rather than an exclusive focus on diagnosis and disease processes.<sup>12,14,17,18</sup> Palliative care experts also support the necessity to integrate an understanding of the undivided and interwoven domains of the whole person. Ferrell and Coyle<sup>40</sup> asserted that human suffering simultaneously engages physical, psychological, social and spiritual domains. These nursing experts contended that human suffering can only be comforted when it is understood as a deeply personal, wholistic, and uniquely-lived human experience. This understanding of whole-person dimensions of life evolves from the effort to sincerely know the other person – in other words, attention to the life-world of the other.

Attention to the life-world of another person entails discovery of who the person is, what relationships and experiences are significant, and how meaning and value in life have been communicated and created. It is necessary that this discovery be a process that is accepting of alternative perspectives regarding life, includes a sincere willingness to listen to the life experiences of another person, and incorporates careful observation of human behavior.

Acceptance of alternative perspectives regarding life is fundamental for creating a milieu of safety and trust. Acceptance is conveyed when a non-judgmental approach is adopted and when the nurse's words and actions are both congruent and consistent. A safe and trusting environment provides the opportunity for freedom of self-expression. When patients and their families feel free to express themselves without fear or reservation, they can candidly discuss matters they perceive to be of importance to life and death.

Active listening skills are also vital for attending to a dying individual. The nurse's use of active listening is important because being heard fosters a sense of being understood, and this is

always a priority concern for patients and their families.<sup>44</sup> A nurse initiates active listening by discontinuing tasks that may be unnecessary and adopting an attentive posture and manner. Additionally, the nurse can employ open-ended communication strategies such as “Tell me about your life’s work” or “I noticed these photographs at your bedside; will you tell me more about your family” to explore the details of a patient’s life. Phrases such as “What do you think about...” or “Help me to understand...” and “Tell me more about...” are also effective when the nurse is communicating sincere interest and is learning about the perspectives of another. Such simple yet powerful phrases followed by attentive listening often unveil many contextual and relational aspects of the patient’s life experience and invite patient-family perspective on matters at hand. Appreciation for unique details that reflect values, experiences, and contributions of dying patients and their families validates personhood and affirms human dignity beyond any disease processes that may be present.

Observation of human behavior is also an important professional skill because observation reveals important patterns of the lived experience. According to Newman,<sup>4(p6)</sup> “the data of pattern are the stories of people and their connectedness to their environment, reflecting the complexity of continuing change.” The living human story is always unique and sacred. Contemporaneous stories reveal important insights about an individual’s preferences, values and beliefs, family and cultural influences, as well as deep personal and social meanings. However, these important and sometimes changing patterns of behavior and response can be easily missed or misinterpreted if the nurse has not honed the skill of attentive observation. When the nurse appreciates the important patterns of patient-family life, he or she is able to respond appropriately yet compassionately during the challenging transformations of the dying experience.<sup>40,43</sup>

## **Regard for Human Relationship**

Human beings are social creatures and relationships are essential to life. Relationships embody a sense of connectedness to significant others and to a higher power.<sup>29,45</sup> This sense of connectedness implies involvement within a network of others with whom it is possible to communicate and with whom one shares mutual obligation, advocacy, and support. Significant relationships help define individuals within the larger universe and make a meaningful life possible.<sup>29,45</sup> Within the boundaries of social-cultural relationships, patterns of language and communication are known; emotions, behaviors and responses are familiar.<sup>35</sup> Likewise, relationships bestow emotional safety and psycho-spiritual support when risks, fears, and challenges of life are experienced. The most intimate relationships in one's life sustain human dignity by offering unconditional love, acceptance, and affirmation.<sup>46</sup> Thus, end-of-life care that emphasizes the importance of relationships supports human wholeness.<sup>29,40,42</sup>

The foundation for relationship-based end-of-life nursing care is the nurse-patient relationship. A genuine nurse-patient relationship sustains and builds upon safety and trust that is created through open acceptance. This sustaining effort is necessary for unmediated and respectful dialogue about dying and death, as well as mutual dialectic regarding appropriate care options.<sup>42</sup> The patient's goals are primary; the nurse's efforts to achieve mutual understanding regarding care assists the patient to realistically attain these goals. For example, when the patient expresses need for pain relief, the nurse can assist by providing the support and education that will help him or her make the best possible personal choices.

A genuine nurse-patient relationship is characterized by mutual understanding and respect. It is also marked by the degree to which the nurse demonstrates regard for other significant relationships in the patient's life. Most people do not face their dying alone; family

and friends accompany them on the journey.<sup>45</sup> When the nurse honors bonds between the patient and his or her significant others, he or she affirms meaning in the everyday living circumstances of the patient and those persons intimate to him or her. This affirmation is essential because social support fosters positive coping and influences adaptation to significant life events.<sup>45,47</sup> When human beings experience unfamiliar or difficult circumstances, they often derive comfort and strength by maintaining connection with what is known and familiar. Family and intimate friends (or sometimes beloved pets) can offer this comfort and strength. Additionally, when the nurse supports individuals who are important to the patient, family coping is enhanced and this helps to preserve integrity within the family unit. For example, education may be provided to family members who can help meet physical or emotional needs of a loved one, or family respite care may be arranged if this is necessary to restore energy needed for ongoing support of the dying patient.

Perhaps the most pervasive of human relationships is embodied in spirituality. Spirituality has been described as the “integrative force” for the existence of human wholeness.<sup>48(p.70)</sup> This integrative force has also been described as soul, essence, life energy, and other similar terms.<sup>46,49,50</sup> Spirituality is not the same as one’s religion, which is an organized system of morals and beliefs. Rather spirituality is inherent in the essence of being. Spirituality has to do with genuineness and depth, and it is expressed through one’s connectedness with God or a higher power, self, others, and nature.<sup>48,49</sup> Regard for relationship at end-of-life includes respect for *all* expressions of the sacred because these expressions have deep root in the mysteries of soul and spirit, and therefore are holy.<sup>50</sup>

Acknowledgement of and reverence for human spirituality has potential to permeate all aspects of personhood. This act of deep respect creates a hallowed space for the patient and

family and this space sustains the courage and grace which are indispensable when theories and tools of science, medicine, and technology become powerless to change what is transpiring. Indeed, the most powerful yet arguably the most difficult act of affirmation of human relationship may be the nurse's quiet presence during moments of existential suffering or in the final moments of life. This act of "being with" another during spiritual transformation communicates shared humanity and expresses profound solidarity.<sup>41,43,46</sup> Neither words nor actions can generate the peace that sincere spiritual solidarity can engender.

### **Nursing Praxis**

Self-awareness, attention to the life-world of another, and deep regard for human relationships are fundamental aspects of hermeneutic understanding. These aspects of understanding have been advocated by palliative care experts because they incorporate the centrality of human wholeness and human dignity. While each individual facet is important for the development of a more complete understanding of human dimensions of care, these aspects are also markedly interwoven. The circular and dialectic quality that exists among them assures that growth in one aspect informs and broadens the horizons of understanding in each of the others. This growth is at once dynamic and expansive. Insights regarding human wholeness often begin as glimpses of understanding derived from the cultivation of self-awareness, attention to others, and regard for human relationships. However, each insight returns again and again to broaden, expand, and inform other facets of understanding. Because of the dialectic and interwoven relationship among these fundamental aspects of hermeneutic understanding, multiple insights have potential to coalesce and fuse into a unity. As a more profound knowledge of the dying experience ensues, authentic patient-centered caring expands in all dimensions. Henceforth, a sense of freedom and openness to possibilities begins to emerge. The what, when,



where, and how to synchronize care becomes more transparent. The nurse is able to maximize benefits of scientific knowledge and technological skill while simultaneously embracing human dignity and wholeness. The art, science, and practice of nursing thus merge into an unbroken unity, and knowledge is transformed into genuinely meaningful action. The resultant nursing praxis offers the possibility for authentic patient-centered end-of-life care.

By cultivating self-awareness, attention to the life-world of others, and deep regard for human relationships – facets of understanding and skills that are grounded in the hermeneutic tradition – the professional nurse is able to foster end-of-life nursing praxis. Therefore, purposeful and active cultivation of each of these skills is recommended. This effort requires personal and team commitment as well as ongoing support from nurse educators and clinical leaders. Several examples follow and these examples will help to illustrate this idea.

Heidegger<sup>34</sup> and Gadamer<sup>35</sup> asserted that language is the foundation for common understanding. A useful strategy that facilitates common understanding among professional team members includes the sharing of end-of-life narratives and patient care experiences. End-of-life narratives explicate the rich, contextual and experiential voices of the patient and family. Team members can expand individual understanding by personal engagement, reflexive thinking, meaningful dialogue, and dialectic regarding end-of-life narratives and personal experiences. Furthermore, allowing time to give “voice” to patient care encounters encourages integration of palliative care knowledge, provides opportunity for exploring different perspectives, and supports common understanding of lived human experiences.

Other strategies foster self-awareness. For example, the understanding that is honed from practices such as mindfulness meditation, personal reflection, deep listening, and presence supports introspection. Training and open dialogue regarding these practices are required in

order to minimize associated fear and uncertainty and to facilitate the transformation of abstract concepts into meaningful practices. This necessitates not only ongoing commitment from the individual nurse, but also the time and support of educators and mentors in an environment conducive to learning.

Many meaningful strategies have supported the development of skills necessary for an understanding of the human condition at end-of-life. Resources that explicate these strategies are plentiful and are widely available in nursing and healthcare literature.<sup>8,40-43,46,48-50</sup> However, the potential benefits that may be yielded from using these resources will remain untapped if the value and power of hermeneutic understanding is not recognized as essential for the development of nursing praxis. Thus, attention to the skills that support hermeneutic understanding must be affirmed, adopted, supported, and fully integrated into end-of-life education, research, and practice. Existing therein is the potential to reclaim care, compassion, and humanity for all dying individuals and their families.

### **Conclusion**

Dying is a unique human experience. The need to expand knowledge and understanding regarding this human experience has been consistently emphasized by patients and their families. This need has been supported by professionals, scholars, and leaders of national and international palliative care organizations. In recent years significant progress has been made to address quality of life for dying individuals, but much work remains to be done in order to achieve patient-centered care. Authentic patient-centered practice is grounded in attention to human wholeness and the human dimensions of care. The nurse's potential for attending to dimensions of human wholeness is fostered by the development of hermeneutic understanding. When capacities for self-understanding, attention to the life-world of others, and appreciation for

human relationships are developed, a dynamic and expanding understanding of the human condition ensues. Thus, embracing hermeneutic understanding is essential for improving quality of life for dying patients and their loved-ones. This understanding supports the possibility for the nurse to use scientific knowledge and technical skill in a manner consistent with patient-family needs and preferences – in other words, authentic *patient-centered* nursing praxis.

**Table 1. Significant Events in the US History of Palliative Care Nursing\***

<b>Timeframe</b>	<b>Publication, Event, Epoch</b>	<b>Significance</b>
Prior to 1900	Life expectancy was less than 50 years.	Most people died at home surrounded by loved ones; emphasis on comfort care.
20 <sup>th</sup> Century	Advancements in science and technology resulted in changes in health/healthcare.	Shift to institutionalized care; denial of death and dying became prevalent in American society.
Mid-1960s	Researchers and scholars began to document challenges of caring for the dying in institutionalized settings.	Concerns surrounding awareness of dying and quality of dying and death in modern society were documented; the topics of dying and death became more widely considered by healthcare scholars as well as the larger society.
Late 1960s	Dr. Cicely Saunders, a physician and nurse opened the first modern hospice, St. Christopher's Hospice in London, England.	This program demonstrated that physical symptoms associated with dying could be adequately managed and that people could die with dignity.
1974	First hospice in America opened in Branford, Connecticut under the leadership of Florence Wald, RN.	Initiated the American hospice movement; hospice has since grown nationally and internationally.
Late 1980s	The Hospice Nurses Association was founded in 1987. In 1998, this was amended to become Hospice and Palliative Nurses Association (HPNA).	This organization fosters professional development and provides professional support for nursing caregivers in hospice and palliative care services.
Early 1990s	Patient Self Determination Act (PSDA) was passed. Dr. H. Brody, a noted physician and ethicist, originated the terminology "assistance in dying" and focused public attention on patient rights for a "good death."	PSDA ensured that hospital patients are informed of their right to make treatment decisions. Public awareness was raised regarding patient rights and end-of-life issues. While patient-requested euthanasia and assisted suicide has been supported by many Americans, it continues to remain widely debated. <b>Effective palliative care remains a recognized alternative.</b>
1995	Publication of Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT).	Documented major deficiencies and inefficiencies in care at end-of-life; emphasized need to improve quality of end-of-life care in all healthcare settings.
Mid/Late-1990s	Institute of Medicine (IOM) convened to address issues surrounding end-of-life; <i>Approaching Death: Improving Care at the End of Life</i> was published in 1997.	IOM report identified end-of-life knowledge gaps; subsequent to the IOM report, many research studies have been conducted and resources have been expended by multiple disciplines to stimulate constructive health system change.
1997	National Institute of Nursing Research appointed to serve as lead Institute at NIH for end-of-life research. NINR established end-of-life care as a priority research endeavor.	Ongoing research and quality improvement fostered and funded. NINR established the Office of Research on End-of-Life Science and Palliative Care, Investigator Training, and Education (OEPC).
1998	The document entitled <i>Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care</i> was published in 1998 by AACN.	End of Life nursing care competencies were developed. Other specialized educational initiatives such as End of Life Nursing Education Consortium (ELNEC) were initiated to develop/provide end-of-life and palliative care education curriculum for nurses.
2004	<i>Clinical Practice Guidelines for Quality Palliative Care</i> were developed by the National Consensus Project (NCP).	Inter-disciplinary standards and guidelines of palliative care were developed in an effort to improve quality of palliative care throughout the nation. In 2007 the National Quality Forum (NQF) endorsed the NCP standards and guidelines.
2009	The NINR <i>Areas of Research Emphasis</i> report was published; end-of-life included as a strategic area for research and knowledge development.	NINR reaffirmed importance of end-of-life research, knowledge development, and quality improvement efforts with emphasis on patients and their caregivers.

\*Excerpted from the works of Bookbinder, Kiss and Matzo,<sup>5</sup> Lenz and Sherman,<sup>7</sup> and the NINR<sup>11</sup> report

**Table 2. Summary of Representative End-of-Life Research: 1999-2009<sup>12-32</sup>**

Reference	Sample and methods	Findings
McSkimming S, Hodges M, Super A et al. The experience of life-threatening illness: Patients' and their loved ones' perspectives. <i>J Palliat Med.</i> 1999; 2(2):173-84.	Participants: Persons with life-threatening illness s/a cancer, AIDS, COPD (n = 77), personal/family caregivers (n = 70), and bereaved persons (n = 81); Total 33 focus groups; Qualitative study; Semi-structured interviews.	5 major themes identified by patients: I am living; dying not medical event; need for more information; I am not afraid-doctor is; Listen to me and listen to my family. 4 major themes identified by family/care providers: It is my illness, I know my loved one; I am exhausted; Afraid of missing doctor.
Singer PA, Martin DK, Kelner M. Quality end-of-life care: Patients' perspectives. <i>JAMA.</i> 1999;281(2):163-8.	Participants: Residents in long term care and patients with end-stage renal and HIV disease (n = 126); Qualitative study; semi-structured interviews.	Five interconnected themes were identified: symptom management, need to strengthen relationships, sense of control, relieving sense of burden, and dying in peace.
Steinhauser K, Clipp E, McNeilly M, Christakis N, McIntyre L, Tulsky J. In search of a good death: Observations of patients, families, and providers. <i>Ann Intern Med.</i> 2000; 132(10):825-32.	Participants: Patient, family, physician, and non-physician health care providers (n = 75); 12 Focus Groups; Qualitative study; focus group discussions and in-depth interviews.	Six major attributes of a good death: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person; Physicians' discussions of a good death differed greatly from those of other focus group members. Physicians suggested most biomedical perspective, while patients, families, and other health care professionals offered a broad range of characteristics integral to quality of dying.
Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. <i>JAMA.</i> 2000; 284(19):2476-82.	Participants: Seriously ill patients (n = 340), recently bereaved family (n = 332), physicians (n = 361), and other care providers including nurses, social workers, chaplains, and hospice volunteers (n = 429). Quantitative study; Cross-sectional, stratified random national survey; 44 attributes (5 point scale) and 9 rankings; compared within and across groups.	Twenty-six items rated as being important (>70% response for importance) across 4 groups: pain/symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a "whole person." Eight items: strong importance ratings from patients but less from physicians (P<.001) for example, not being a burden, and coming to peace with God; "Being treated as a whole person" was among categories identified by all groups; Some similarities noted among groups but factors related to quality at end of life differ by role and by individual.
Bolmsjo I. Existential issues in palliative care: Interviews of patients with amyotrophic lateral sclerosis. <i>J Palliat Med.</i> 2001;4(4):499-505.	Participants: Patients diagnosed with ALS (n = 8). Qualitative study; interviews.	Five themes: meaning and guilt; relationship; diagnosis and information; physical inability; dying with dignity/ respect for the person. Patients experience a number of problems in connection with physical inability; need to confide in someone not necessarily strong; central for value of life to be respected as a person; existential issues are of great importance to the patients.

Farber SJ, Egnew TR, Herman-Bertsch JL, Taylor TR, Guldin GE. Issues in end-of-life care: patient, caregiver, and clinician perceptions. <i>J Palliat Med.</i> 2003;6(1):19-31.	Participants: Patients (n = 42), caregivers (n = 39), physicians (n = 39) Qualitative study; in-depth, open-ended, face-to-face interviews and content analysis.	4 major clinician/patient/caregiver themes: awareness of death, management/coping with daily living, relationships, and personal experience with EOL; Perceptions of patients, caregivers, and physicians have similarities, but differ significantly in emphasis based on perspective/ physician focus mainly on diagnosis and plan of care.
Wenrich MD, Curtis JR, Ambrozy DA, Carline JD, Shannon SE, Ramsey PG. Dying patients' need for emotional support and personalized care from physicians: Perspectives of patients with terminal illness, families, and health care providers. <i>J Pain Symptom Manage.</i> 2003;25(3):236-46.	Participants: Individuals, including patients with chronic and terminal illnesses, family members, health care workers, and physicians (n = 137); 23 focus group; Qualitative study; Content analyses.	12 domains of emotional support identified; Emotional support and personalization were 2 of the 12 domains identified for emphasis. Most frequently raised category of personalization among all focus group categories except health care workers was that physicians treat the "whole person, not just the disease."
Carter H, MacLeod R, Brander P, McPherson K. Living with a terminal illness: patients' priorities. <i>J Adv Nurs.</i> 2004 Marc;45(6):611-20.	Participants: Patients with terminal illness (n = 10); Qualitative study; non-directive interview style/narrative.	Central overarching theme was taking charge; study found diversity of experiences within and across individuals. Five inter-related themes were identified: personal/intrinsic factors, for example participation in daily activity; external/extrinsic factors, for example relationships; future issues, such as life plans; perceptions of normality, such as using time before onset of illness as reference point for living with dying; taking charge, such as fulfilling needs re life function and realizing philosophical position re meaning of life.
Vig EK, Pearlman RA. Good and bad dying from the perspective of terminally-ill men. <i>Arch Intern Med.</i> 2004;164(9):977-81.	Participants: Men with terminal heart disease or cancer (n = 26); Qualitative study; semi-structured interviews regarding views of good and bad death.	Multiple themes of good/bad death emerged; participants did not hold a uniform view of good or bad death; multiple reasons emerged for how themes contributed to good/bad death; past experiences with death and inadequately controlled symptoms influence participant's views of good/bad death.
Wilson KG, Curran D, McPherson CJ. A burden to others: A common source of distress for the terminally ill. <i>Cogn Behav Ther.</i> 2005;34(2):115-23.	Participants: Patients with advanced cancer ; (n = 31) men, (n = 38) women; Quantitative study; data collected using 13 - item Structured Interview of Symptoms & Concerns.	Sense of self-perceived burden found to be a common experience; reported by 39.1% as minimal or mild concern; by 38% as a moderate to extreme concern. Sense of burden showed a low correlation with physical symptoms (r = 0.02-0.24) and higher correlations with psychological (r = 0.35-0.39) and existential issues (r = 0.45-0.49). Comparisons of participants with high or low levels of self-perceived burden showed the importance of this factor for overall quality of life.

<p>Aspinal F, Hughs R, Dunckley M, Addington-Hall J. What is important to measure in the last months and weeks of life?: A modified nominal group study. <i>Int J Nurs Stud.</i> 2006;43(4):393-403.</p>	<p>Participants: Patients (n = 10), professionals (n = 35) bereaved relatives (n = 30); Total 10 focus groups; Qualitative study; modified nominal group technique; structured discussion.</p>	<p>Seven themes identified as most important to participants: symptom management; choice and control; dignity; quality of life; preparation; relationships; and co-ordination and continuity. Bereaved relatives and professionals Identified three themes: symptom management, relationships and quality of life.</p>
<p>Heyland DK, Dodek P, Rocker G, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. <i>CMAJ: Canadian Medical Association Journal</i> 2006;174(5):O1-O9.</p>	<p>Participants: Patients who were elderly, or diagnosed with advanced cancer and end-stage medical disease (n = 440), and family members (n = 160); 5 hospitals; Quantitative study; Survey; Questionnaire with face to face administration.</p>	<p>Factors rated most important by patients: trust in physicians (55.8%), not to be kept alive on life support (55.7%), communication (44.1%), life completion (43.9%), continuity of care (41.8%), not to be burden (41.8%); Significant differences between patient groups and between patients and family members.</p>
<p>Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Dignity in the terminally ill: revisited. <i>J Palliat Med.</i> 2006;9(3):666-72.</p>	<p>Participants: Patients (n = 211) asked the extent to which they believed specific issues were or could be related to their sense of dignity; Quantitative study; results used to validate Dignity Model.</p>	<p>Themes and subthemes from the Dignity Model used to devise 22 items; "Not being treated with respect or understanding" (87.1%) and "feeling a burden to others" (87.1%) were the issues most identified as having an influence on dignity; Demographic variables s/a religious affiliation had an influence on what items patients ascribed to their sense of dignity. "Feeling life no longer had meaning or purpose" was the only variable to enter a logistic regression model predicting <i>overall</i> sense of dignity.</p>
<p>Coyle N. The hard work of living in the face of death. <i>J Pain Symptom Manage.</i> 2006;32(3):266-74.</p>	<p>Participants: Patients at an urban cancer research center who were living with advanced disease (n = 7); Qualitative study; interpretive phenomenology; semi-structured interviews.</p>	<p>Three themes: reflected the hard work that these individuals undertook. Themes included orientating themselves to the disease and maintaining control, searching for and creating a system of support and safety, and struggling to find meaning and create a legacy.</p>
<p>Fitzsimons D, Mullan D, Wilson JS et al. The challenge of patients' unmet palliative care needs in the final stages of chronic illness. <i>Palliat Med.</i> 2007;21(4):313-22.</p>	<p>Participants: Patients with diagnosis of end-stage heart failure, renal failure or respiratory disease (n = 18). Short Form 36, Hospital &amp; Anxiety Depression Questionnaire completed by patients to evaluate functional and emotional status. Unstructured interviews (n = 35) conducted separately with each patient &amp; significant other. Interviews followed by focus group discussion (n = 18) with multi-professional team. Quantitative and Qualitative methods.</p>	<p>Central Theme: Deteriorating health status leading to decreased independence, social isolation and family burden; problems were mitigated by the limited resources at the individual's disposal and the availability of support from hospital and community services. Generally resources and support were perceived as lacking.</p>



<p>Chochinov HM, Kristjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Burden to others and the terminally ill. <i>J Pain Symptom Manage</i>. 2007; 34(5):463-71.</p>	<p>Participants: Patients with end-stage cancer (n = 211); assortment of validated psychometric tools to document psychosocial, physical, and existential aspects; Quantitative study; descriptive and inferential statistics.</p>	<p>40% participants with negligible sense of burden to others, scoring lowest quarter on an ordinal measure of "burden to others;" 25% scored 2nd lowest quarter; 12% within 3rd quarter; and 23% within highest or most severe range. Most highly correlated variables with "sense of burden to others": depression (P&lt;0.0001), hopelessness (P&lt;0.0001), and outlook (P&lt;0.0001). Four variables emerged in multiple regression analysis predicting burden to others, including hopelessness, current quality of life, depression, and level of fatigue [R(2) adj=0.32, F(6,174)=13.76, P&lt;0.0001]. No association between sense of burden to others and actual degree of physical dependency.</p>
<p>Reinke LF, Engelberg RA, Shannon SE, et al. Transitions regarding palliative and end-of-life care in severe chronic obstructive pulmonary disease or advanced cancer: Themes identified by patients, families, and clinicians. <i>J Palliat Med</i>. 2008;11(4):601-9.</p>	<p>Participants: Patients n = (55), family members (n = 36), physicians (n = 31), and nurses (n = 25). Qualitative study; semi-structured interviews followed by follow up interviews at two points in time.</p>	<p>Six themes identified re participants' transitions: Themes that defined <i>transitions</i> among both patients with COPD and those with cancer included: new/different treatments and no more treatments available. Themes unique to patients with COPD were activity limitations due to functional decline and initiation of oxygen therapy. Patients and families differed in perspectives re transitions compared with care providers; physicians and nurses assigned different meanings.</p>
<p>Prince-Paul M. Understanding the meaning of social well-being at the end of life. <i>Oncol Nurs Forum</i>. 2008;35(3):365-71.</p>	<p>Participants: Patients who were terminally ill with advanced cancer (n = 8); Qualitative study; In-depth semi-structured interview to explore meaning of social well being.</p>	<p>Six themes emerged that described the meaning of close personal relationships at the end of life: meaning of relationships with family, friends, and coworkers; meaning of relationships with God or a higher power; loss and gains of role function; love; gratitude; and lessons on living.</p>
<p>Back AL, Young JP, McCown E, et al. Abandonment at the end of life from patient, caregiver, nurse, and physician perspectives: Loss of continuity and lack of closure. <i>Arch Intern Med</i>. 2009;169(5):474-9.</p>	<p>Participants: Patients with incurable cancer or advanced chronic obstructive pulmonary disease (n = 55), family caregivers (n = 36), nurses (n = 25) and physicians (n = 31);. Longitudinal qualitative study; community-based; 3 semi-structured interviews.</p>	<p>Focus on hope and prognostic information resulted in participants spontaneously raising concerns about abandonment; abandonment incorporated into our interview guide. Findings: Two themes were identified: before death, abandonment worries related to loss of continuity between patient and physician; at the time of death or after, feelings of abandonment resulted from lack of closure for patients and families. Physicians reported lack of closure but did not discuss this as abandonment.</p>
<p>Chochinov HM, Hassard T, McClement S, et al. The landscape of distress in the terminally ill. <i>J Pain Symptom Manage</i>. 2009; 38(5):641-49</p>	<p>Participants: Palliative care patients from three recruitment sites (n = 253). Quantitative study; used assortment of psychometric tools, including Patient Dignity Inventory (PDI); descriptive and inferential statistics.</p>	<p>Patients reported an average of 5.74 issues causing distress at end of life. Sources of distress at end of life included a combination of physical challenges, functional limitations, and existential concerns.</p>



<p>Downey L, Engelberg R, Curtis R, et al. Shared priorities for the end-of-life period. <i>J Pain Symptom Manage.</i> 2009; 37(2):175-88.</p>	<p>Participants: Three samples of patients with advanced life-limiting or terminal illness (n = 352) and their family member or friend/partner (n = 318). Quantitative study; used the Preferences about Dying and Death (PADD) interview to assess importance of characteristics at the end-of-life period in order to refine a psychometric instrument; descriptive and inferential statistics.</p>	<p>End-of-Life priority rankings included 26 scores for the merged samples. Eight items in the high priority group included: spending time with family and friends, pain control, breathing comfort, maintaining dignity and self-respect, being at peace with dying, human touch, avoiding strain on loved ones, and avoiding life support. Two items represented top priorities for all subgroups: time with family and friends and pain control.</p>
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Chapter 3  
(Manuscript 2: Study Findings)

Understanding Nurses' Experiences of Providing End-of-Life Care in the United States Hospital Setting

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## **Understanding Nurses' Experiences of Providing End-of-Life Care in the United States**

### **Hospital Setting**

Of the citizens in the United States (US) who die annually, over 40% of these individuals expire in the hospital setting.<sup>1</sup> Projections from the 2008 US Census Bureau Report indicate that this percentage of individuals will most likely rise over the next 30 to 40 years.<sup>2</sup> As care providers, nurses are in an important position to influence the quality of care for dying patients and their families. Because nursing care is so vital, numerous researchers and clinicians have recommended that systematic exploration take place into actual experiences and reflections of nurses who care for terminally-ill persons.<sup>3-5</sup> These recommendations suggest that the findings of such investigations would be reliable sources from which to build support for continued advancement of compassionate and holistic end-of-life care. However, few studies have explored the experiences and reflections of nurses in the hospital setting. The purpose of this study was to explore the experience of end-of-life care in the inpatient hospital setting from the perspective of the registered nurse. Hermeneutic phenomenology was utilized because this approach facilitates greater understanding of matters significant to the human condition, such as care at the time of dying and death.<sup>6</sup>

### **Background**

As early as 1965, significant issues surrounding the awareness and quality of dying and death in western society had been described.<sup>7</sup> At that time, in spite of public and professional concerns about the appropriate use of life-extending technology and mounting evidence regarding the anguish associated with terminal illness, little progress was made by the healthcare community to address this complex phenomenon. Two important initiatives offered the promise of dignity and quality care for terminally-ill patients. First, during the mid-1970s the hospice

movement was introduced and advanced in the United States. Hospice care offered a holistic alternative to the highly technical, depersonalized approach that had become dominant in the western health care system.<sup>8</sup> The second initiative was the commencement in this country of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) accompanied by its companion research efforts.<sup>9,10</sup> However, it was not until 1995 that the results of the SUPPORT study were published, revealing major deficiencies and inefficiencies in end-of-life care.

Subsequently, the Institute of Medicine (IOM) developed and disseminated a landmark publication entitled *Approaching Death: Improving Care at the End of Life* in order to reform end-of-life care.<sup>11</sup> A major goal of the IOM was to stimulate constructive health system change by “strengthening popular and professional understanding of what constitutes good care at the end of life and by encouraging a wider social commitment to caring well for people as they die”<sup>11(p1)</sup> Funding provided by the National Institutes of Health (NIH) and other major organizations, such as the Robert Wood Johnson Foundation (RWJF), stimulated additional interest for research and health care improvement in the area of end-of-life care. Since publication of the SUPPORT study and IOM report, considerable resources and efforts have been expended by many professional disciplines to resolve the gaps in end-of-life care.<sup>9-11</sup> These research efforts contributed significantly to the development in 2004 of contemporary interdisciplinary palliative care guidelines. These guidelines which were updated in 2009 disseminate from the National Consensus Project for Quality Palliative Care (NCP).<sup>12</sup>

The NCP<sup>12</sup> guidelines for palliative care build upon the original template of hospice care; however, they offer a holistic focus of care for patients and their families facing serious life-threatening or debilitating illnesses across the lifespan, regardless of care setting or stage of the



patient's illness.<sup>8,12</sup> The guidelines emphasize effective management of pain and other distressing symptoms while integrating psychosocial and spiritual care with consideration of patient and family needs, preferences, values, beliefs, and culture.<sup>12</sup> As the practice and evidence of palliative care continues to grow, these standards have been adopted within mainstream health care, including hospital settings.<sup>12</sup> Formal educational programs that reflect the standards have also been developed. The End-of-Life Nursing Education Consortium (ELNEC) is an example of an educational initiative that affords nurses the specialized training needed to provide comprehensive quality care to patients and families facing terminal illness.<sup>13</sup> The original core ELNEC curriculum was developed in 2000. This program of study has since undergone expanded development in order to address educational needs within diverse healthcare settings, such as medical-surgical units, critical care, and geriatric units within the inpatient hospital setting.<sup>14</sup>

Research on the experiences of nurses who provide care for terminally-ill patients and their families in the hospital setting is limited. Many recently published research studies regarding the experiences of nurses in the US (2005-2010) have focused on specific aspects of end-of-life care, problematic care processes, or nursing education.<sup>15-24</sup> Yet personal accounts of nurses are not often recorded or examined. This qualitative research study was conducted to explore the first-hand experiences of registered nurses who provide care for dying patients and their families in the hospital setting. These narratives help provide a better understanding of the nurses' end-of-life care experiences and offer opportunities to improve end-of-life nursing care. Therefore, this study addressed the following research question: "Among nurses who provide end-of-life care for adults in inpatient hospital settings within the United States, what are their understandings of those experiences?"

## Methods

Hermeneutic phenomenology was used as the research design for this study. The philosophical perspectives of Hans Georg Gadamer (1900-2002) are the underpinnings for hermeneutic phenomenology.<sup>25</sup> Gadamer's philosophical works contributed to an appreciation of the vital role of human understanding and meaning-making as central to the human condition through a focus on the relationship of human beings to their life-world. Contemporary human science recognizes hermeneutic phenomenology as both a philosophy of understanding and a method of scientific inquiry.<sup>26</sup> Phenomenology is concerned with the lived human experience in all of its richness, while hermeneutics is the art of interpretation and is undertaken in an effort to explore the *meaning* of lived experiences.<sup>27</sup> Because this approach aims to uncover and interpret the deeper meanings of lived human experiences, it provides a solid foundation for exploring the experiences of nurses who provide care for terminally-ill patients and their families.

The research methods outlined by Max van Manen<sup>6</sup> are consistent with the philosophical perspectives of Gadamer.<sup>27</sup> These methods are phenomenological, hermeneutic, and language-oriented. van Manen<sup>6</sup> described the interpretive approach to understanding as textual reflection on the lived experiences and practical actions of everyday life with an intent to find meaning and make greater sense of significant aspects of human existence. As a method of inquiry, van Manen's<sup>6</sup> human science approach emphasizes dialogue and dialectic between the perspectives of the researcher and the perspectives of the study participants; both oral narrative and written text are considered to be important. Thus, the methodology delineated by van Manen<sup>6</sup> informed the conduct of the current study throughout all phases. The investigator initiated the endeavor by turning to the nature of end-of-life care and by identification of personal pre-understandings, and

she continued to use van Manen's<sup>6</sup> guidelines through the subsequent phases of data collection, data interpretation, and writing of the study findings.

### **Investigator Pre-understandings**

Research influenced by Gadamerian<sup>25</sup> philosophy and guided by van Manen's<sup>6</sup> methods emphasizes the significance of the investigator's pre-understandings and assumptions. The collective works of these scholars indicate that bracketing of personal background and understandings is both impossible and impractical. Rather, the explication of personal pre-understandings and assumptions is not only necessary but is absolutely integral to the process of hermeneutic understanding.

The investigator's perspective included being a registered nurse for over 30 years and having had extensive experience in the hospital environment. A broad clinical, educational, quality-improvement, and leadership background afforded the investigator a lens through which multiple aspects of end-of-life care in the hospital setting were viewed. Furthermore, the same vantage point provided an opportunity for the investigator to recognize the critical significance of this subject for contemporary healthcare. The investigator has had positive personal and professional experiences in caring for individuals at end-of-life, and these experiences have likewise contributed to an ongoing interest in this important aspect of nursing care. The aforementioned experiences as well as multiple other clinical endeavors throughout the years have resulted in an admitted bias for holistic and integrated nursing care. Recent educational pursuits by the investigator have included participation in immersion studies in caring-healing theory and psycho-spiritual care of dying patients and their families. Finally, personal interactions with registered nurses throughout many years of hospital service influenced the decision of the investigator to seek the unique perspectives that may be offered by those

individuals who provide intimate care on a day-to-day basis. The investigator believed that nurses' experiences would provide an opportunity to explore the deeper meanings of contemporary end-of-life care within the hospital setting.

### **Human Subjects Protection**

Approval for this study was obtained from the Institutional Review Board (IRB) of Virginia Commonwealth University, Richmond, Virginia. Interested individuals were informed in writing about the details of the study and their rights as participants. Prior to conducting the interview with each participant, the investigator provided an opportunity for verbal clarification regarding the study and obtained written informed consent. Confidentiality was maintained at all times throughout the study.

### **Participants**

A purposeful and convenience sampling strategy was used to facilitate recruitment of participants from a variety of inpatient nursing units within academic medical center and community hospital settings in one area in the mid-Atlantic region of the United States. After obtaining necessary approvals, the investigator distributed IRB-approved information flyers describing the study to inpatient nursing units within the community, local chapters of professional organizations, community nurse leaders, and personal professional colleagues who had demonstrated an interest in the subject matter. Individuals who were interested in participating in the study contacted the investigator who then screened each potential participant for the following inclusion criteria: (a) currently employed as a registered nurse (RN) within an adult inpatient clinical care area; (b) having participated in an end-of-life training program such as ELNEC or having participated in other end-of-life education or training; (c) having provided direct patient care for adult inpatients after completion of end-of-life training or education; (d)

understanding, reading, and speaking the English language. The inclusion criteria were established to ensure that study participants had had education and experience related to end-of-life care in the hospital environment, which was the phenomenon of interest. Inclusion criteria also provided assurance that a basic understanding of English language and familiarity with contemporary palliative care guidelines served as a common foundation for all participants.

The investigator recruited and enrolled participants until variation in current work settings was represented and data saturation was achieved. A total of 20 registered nurses who met inclusion criteria and who indicated interest in the study received information materials. Seven of these individuals were not enrolled. Personal responsibilities or conflict in scheduling a face-to-face interview influenced the decision for 4 individuals who did not enroll; the remainder of them did not offer an explanation for their disinterest in study participation.

The final study sample included a total of 13 RN participants. Twelve participants were female and one was male. Eleven participants were Caucasian, 1 person was Hispanic, and 1 person was Pacific Island-Asian. The ages of the participants ranged from 28 to 62 years of age; the average age was 46 years. The participants were employed in a variety of inpatient clinical settings; however, 6 of the participants had extensive experience in multiple and different hospital or clinical settings throughout their nursing careers. All of the participants had exposure to the ELNEC curriculum or end-of-life standards; 85% had completed the formal ELNEC curriculum while 15% of the participants had received education regarding end-of-life care in the work setting. The demographic characteristics of participants are delineated in Table 1.

### **Data Collection**

Data collection for this study occurred from July through November 2009. All individual interview sessions were scheduled during a time period and at a private place that were selected

by the participant. Prior to the interview, a data form was given to each individual to gather demographic information. Participants were reassured that all personal data would remain confidential.

Interviews took approximately 60 to 90 minutes and were audio-taped using a digital recorder with the permission of the participant. Using a semi-structured, interactive approach, each individual was asked by the investigator to (a) describe his or her nursing background and details regarding original and ongoing interests in end-of-life nursing care; (b) share meaningful end-of-life nursing care experiences; and (c) share any additional thoughts, reflections, recommendations, or information regarding the subject of end-of-life care. Clarification of narrative information was requested as necessary and additional open-ended questions were asked by the investigator in a conversational and dialectical style to elicit expansion of ideas that had been presented.<sup>6,25</sup> Dialogue was balanced with periodic silence to encourage reflection and to allow the participant an opportunity to focus on contextual details of personal experiences. Throughout each interview the investigator remained engaged and attentive to verbal and non-verbal behaviors or other cues that might provide understanding of the deeper meanings or significance of the personal experiences being shared by the participant.<sup>6</sup> Interviews ceased when the dialogue came to a natural ending; however, each participant was invited to discuss anything else that he or she perceived to be relevant to end-of-life nursing care.

Interviews were transcribed verbatim to text by a professional transcriptionist who had completed university-approved human subjects' protection training. Each transcript was then read by the investigator while simultaneously listening to the audio-tape and corrections were made to ensure accuracy of textual data.<sup>6</sup> In addition to the recorded interviews and verbatim

transcripts, field notes that were recorded at the time of the interview and the investigator's reflective notes were also used as data for the study.

### **Data Analysis**

Data were analyzed according to the methods outlined by van Manen.<sup>6</sup> According to van Manen<sup>6</sup> data analysis is a dynamic process of discovery in response to the research question at hand. The investigator commenced this phase of the investigative inquiry by repeatedly listening to each audio-taped interview session. Hearing each participant's voice and noting particular expressions and inflections helped to re-create the details of the interview.

The investigator turned to additional phases of the discovery process by considering the textual data within the transcripts.<sup>6</sup> The investigator's field notes that had been recorded at the time of each interview were also considered. The first step in the data analysis process was to read each transcript multiple times in its entirety. The investigator considered the text as a whole while reflecting on possible meanings that had been expressed by the individual participant. Secondly, a selective reading approach was used. Key statements, phrases, and ideas that seemed to reveal aspects of the particular end-of-life care experience were noted. The investigator wrote notes in the margins of the transcripts and highlighted significant statements and phrases that seemed to capture the meaning of the experience. Thirdly, the investigator completed a line-by-line reading of the transcript and examined meanings within each statement in relation to the text as a whole.

The process of data collection and data analysis was iterative. As each individual interview was completed, the investigator became immersed in reading, reflecting, re-reading, and recording personal ideas and intuitions regarding the participant's narrative. Themes were identified and aspects of the narrative that made the experience unique for the individual were

noted.<sup>6</sup> The essence of each participant's experience was then described in an interpretive anecdotal summary and representative quotations from his or her narrative were selected to support the description.

After considering the meanings within individual participant's narratives, the investigator focused attention on the whole of the 13 transcripts. Common essential themes and shared meanings were identified across the transcripts as the investigator continued to move between parts and whole in a hermeneutic spiral of understanding.<sup>6,25</sup> This dynamic and iterative process guided the discernment of themes and sub-themes that described the experiences of nurses providing care at end-of-life in the inpatient hospital setting.

### **Research Findings**

The experiences of the participants were unique and varied. However, three distinct yet interwoven themes described participants' experiences across all settings: "Confronting Challenges," "Coming to Understand End-of-Life Care," and "Transforming the Understanding of End-of-Life Care into Nursing Practice." The findings highlighted in this paper are a summary of three key themes as well as related sub-themes. The narratives of the nurse participants underscored that genuine quality resulted from the integration of scientific knowledge and skill in conjunction with a deep understanding of human dimensions of care.

#### **Confronting Challenges**

The nurses who took part in this investigation confronted many diverse, complex, and inter-connected end-of-life care challenges. These challenges often resulted in personal and professional "struggles" and frequently gave rise to powerful emotional responses which clearly consumed the energies of the participant. The most intense of these challenges generally involved human interactions and human aspects of care. The two related sub-themes that were



identified included “Witnessing Suffering, Experiencing Struggle” and “Emotional Consequences of Nurses’ End-of-Life Struggles.”

### ***Witnessing Suffering, Experiencing Struggle***

The texts suggested that participants experienced a number of challenges and struggles. They often witnessed intense suffering or futile care of patients or family members. Participants struggled when they assessed their skills as inadequate for complex end-of-life needs or when they experienced personal or professional conflict over care choices for their patients. For example, the participants commonly witnessed suffering of patients, family members, and fellow team members. One participant described the difficulty of witnessing the physical decline of a patient with a steady downward trajectory:

*That was hard because she didn't go very fast. It was long...It was difficult...Watching her deteriorate down, down and become like a skeleton...she couldn't eat anything. I have a hard time with people suffering. That's harder than watching them die (Participant-6).*

In a narrative describing the family dynamics of a young man who was dying in an Intensive Care Unit (ICU), another participant highlighted the anguish of bearing witness to a family member's emotional suffering:

*It was hard for me as the nurse....because we would see his dad come into our unit...and see his son in a open ward at the end of the hallway, and he would say, 'Hey J\_\_, it's Dad here! Everything's gonna be OK!' And he would start out with that, and then he would be sitting there at the bedside...working on his laptop with tears running down his face. And I think for me...it was still hard witnessing that. Bearing witness to that father's pain...that he was losing this son that he loved....I think that's what made it hard...was bearing witness (Participant-7).*

Likewise the same participant shared another challenge that she had experienced – that of bearing witness to the turmoil of her colleagues. She had seen many nurses and physicians endure emotional hardship as they confronted distressing end-of-life issues:

*It's not an easy thing to watch someone die...and, I've seen [colleagues] who struggle so much with it that... it's hard for me to watch them just struggle.*

The participants in this investigation also highlighted the difficulty of providing futile care or treatment that they interpreted as prolonging a patient's suffering. One nurse shared an example in a narrative describing care for a middle-aged woman with end-stage respiratory disease:

*So she ended back up back on the ventilator... and we knew she wouldn't come off that time and indeed she didn't...she was uncomfortable. She had to be uncomfortable... You know where do you go with that? [There] was no easy answer...It was just really, really, really sad because this lady died a horrible death when it was not necessary. And we finally did after 3 or 4 days get her off the ventilator and let her go. [It was a] sad, sad, situation (Participant-9).*

In addition to dealing with the anguish of human suffering, the narratives of these participants revealed that considerable distress resulted when they lacked the knowledge or skill to address end-of-life patient care concerns. For example, complex symptom management and communication issues are common when patients are dying. One participant described an experience in which vital nursing energy was consumed by feelings of inadequacy:

*I think I had a hard time because I wasn't sure what I was doing...everyone had a different perspective on how to take care of patients, but...I wanted to know what was the right thing to do ...and I just felt kind of inadequate ...I could assess my patients and I knew what was bothering them, but I didn't know what to ask for from the physician [to manage their end-of-life issues]. I think the communication for me was very hard, and I struggled. If the patient said 'Am I dying?' I always wanted to say, 'What did your doctor tell you?' (Participant-11)*

Another nurse with over ten years of clinical experience echoed similar sentiments. This participant emphasized that a personal lack of understanding about complex human interactions often resulted in a “juggling” act in order to manage countless end-of-life issues:

*Well, when you are in school, you are taught how to do things, you are taught how to assess situations, how to prioritize...very little time is spent on the human interaction, not just with the patients...with the doctors, with the families, with the friends...there's a whole gamut of people you have to deal with... It's juggling, you juggle everybody and everything. [And] sometimes I can't, sometimes I can't...make everybody happy (Participant-13).*

Other texts illustrated that participants routinely encountered diverse personal or professional conflicts when providing care for dying patients. Such conflicts originated from differences in perspectives over care choices or interdisciplinary team dynamics. For instance,

one nurse experienced intense conflict over a family member's decision to continue complex wound care for her terminally-ill sister. This account revealed that a "fine line" existed when the participant advocated for values that were different from her personal values and from usual standard of care:

*It was very sad...she was on all kinds of drips and everything because of this wound. It was difficult to be her care provider and to advocate for the sister's view point... I felt like she probably **wasn't** making the right decision for the patient's well being. I felt like she probably was making the right decisions based on what she **thought** the sister would want though... it was a fine line and it was a struggle...you know, it was a struggle...to really try to be supportive of the sister...and the decision the sister was making, yet that is what I did (Participant-2).*

Conflict sometimes ensued when perspectives of care differed among professional care providers. Participant 3 emphasized that bedside nurses frequently know significant information regarding the needs of patients and their families. She stressed the vital importance of including the nursing perspective, particularly when care planning is effected for the terminally-ill person. This participant also pointed out that energy may be expended on unnecessary care and treatment, frustrations may mount, and team conflicts over care planning can ensue when the nursing "voice" is not heard or heeded. In a narrative describing the death of a young married woman, this participant shared details of conflict and suffering that resulted when the medical focus remained on treatment and cure. The need for collaboration with other health team members such as nursing was also highlighted:

*It was the most somber funeral march...we just weren't able to come out and strongly sit down as nurses in the multidisciplinary setting until the very end...the focus was on cure and control for so long...there was little acknowledgement [of nursing perspective] ... from the physicians, from the family (Participant-3).*

Indeed, the texts illustrated a diversity of challenges and struggles confronted by participants who provided care for terminally-ill patients in the hospital setting. A comment made by one of the nurses in this study reflected this actuality. She suggested that the potential for challenge and struggle at end-of-life is not only diverse but is also infinite and unpredictable:

*When someone is dying, people don't always follow a pattern and I think that the unpredictability of it makes many nurses uneasy....I think that...makes taking care of dying patients tough. You can't predict how the family is going to respond. You can't predict how the patient's going to die. It's just always some sort of mystery about it. And that's hard for people who like to be in control...nurses like to be in control and... we can't control this (Participant-7).*

### ***Emotional Consequences of Nurses' End-of-Life Struggles***

The narratives revealed that emotional consequences often ensued when the participant struggled with the challenges of end-of-life care. Within the narratives, participants expressed diverse sentiments. For example, one participant conveyed a feeling of inner turmoil that had persisted for years after making a decision to close a terminally-ill patient's doorway:

*[I closed the door] and it couldn't have been 30 minutes later, I just felt like 'Oh, I need to look at him.' When I opened the door, he was gone...and I felt guilty about that...like 'did I cause that?' He was in that dark room all by himself...that bothers me...even now (Participant-13).*

Other nurses in this study described similar feelings of guilt when medication or treatment outcomes were less than optimal. One participant suggested that these feelings are often influenced by an overwhelming sense of accountability for patient outcome:

*I think because you are at the bedside, the family is looking at the nurse. You're the one there, so if the physician comes in....and they leave, the nurse is left. I think we feel responsible for our patients. We want them to be comfortable and we want to do everything that we can...so if things aren't going well we kind of say 'well what are we doing [wrong]?' (Participant-11)*

The narratives also highlighted other emotional consequences of end-of-life nursing care such as when circumstances of death were unanticipated or tragic. Participant 2 recalled details of a young patient who died after being admitted to an ICU for a severe reaction to a common medication. As she summed up this experience, she revealed the heartrending personal impact:

*I mean we tried everything. The [physicians] tried everything...and she just de-compensated so rapidly there was nothing...I mean the whole unit was devastated... it was just a horrible, horrible situation, and that was not a good experience for me...because it happened so quickly, you know the end of life...but trying to be supportive to the family under those circumstances. It was just a really, really bad situation...and I don't know that any amount of training would have made a difference...it was horrible...it really brings tears to my eyes...just to think about it.*

This participant indicated that the acute and emotionally intense circumstances of care in the situation illustrated above had been overwhelming for her and other members of the healthcare team.

The texts revealed that physical demands of nursing coupled with the emotional demands of end-of-life care can also take an emotional toll upon the nurse. One participant noted that working long and demanding hours, such as 12-hour shifts, can be particularly difficult when compounded with stress caused by end-of-life care or conflict. The narrative of this nurse suggested that extreme physical and emotional fatigue or feelings of resignation can also ensue:

*It was a big stressor to have the friction between the wife and the physician...we were right smack dab in the middle...It was just very, very stressful...the emotional part of that in addition to working long hours... then once it was over...you just [felt] like the wind [was] gone out of your sails... And after 32 years, you just learn to deal with it... sometimes you have to just go to a quiet corner and pull yourself together and say, 'Well...we did everything that we could do and this is the way it turned out and this is just the way it was meant to be' (Participant-9).*

Another everyday occurrence in the acute care hospital setting is the 'Code Blue.' When resuscitation efforts are initiated, the emphasis shifts to procedural aspects of care. Participant 8 described personal feelings of dismay that had frequently been encountered when the care of patients had become depersonalized during resuscitation procedures:

*Like in my experience [resuscitation]...the ribs cracking, the facial expressions, all this contortion of the body... [the patient] becomes...depersonalized...non-human...and they're not that warm person talking to you about what's on the TV or whatever. All of a sudden...it almost goes back to [focus on fixing] and it's like, what happened to this person...I think that's kind of terrible...I don't know how else to explain it... [It is] just very depersonalized.*

Other strong emotions were also noted within the narratives of these nurses. For example, the texts revealed that some nurses felt anger and blame toward other care providers for giving "false hope" to patients and families and for contributing to "devastation" or despair at the time of death. Feelings of frustration were sometimes triggered because of the "huge responsibility" shouldered by nursing for end-of-life care. The death of certain patients had been "hard" or "difficult", particularly if the nurse had become "close" to him or her. The narratives also

revealed the need for “closure” after patient death and the myriad of human feelings associated with grieving. However, in spite of the intensity or diversity of challenges, it was evident that these patient care situations often markedly influenced participants’ aspirations to help patients to “die well” within the hospital setting. Facing these challenges also strengthened participants’ efforts to seek opportunities that might provide a deeper understanding of end-of-life care.

### **Coming to Understand End-of-Life Care**

The texts revealed that a range of participants’ experiences had contributed to their understanding of end-of-life care. The participants described both positive and negative experiences, yet memories of these experiences often became touchstones bringing clarity and compassion to their work with dying patients and their families. Regardless, multiple and diverse learning opportunities expanded understanding and deepened participants’ sensitivity for humane end-of-life care. Two sub-themes described the participants’ experiences of coming to understand end-of-life care: “Opening to the Learning Experiences” and “Cultivating Significant Insights.”

#### ***Opening to the Learning Experiences***

The texts were replete with examples of pivotal learning experiences that influenced the participants’ understanding of end-of-life care. For some, their personal or family experiences with dying and death were notable; for others, significant or accumulated professional experiences had been influential. Still others commented that mentors and role models in the working environment had been supportive. A common thread among all of the nurses in this study was participation in education or training, such as ELNEC or other educational activities.

When personal and family encounters with dying and death had significantly influenced participants’ understanding of care, these individuals had entered the ‘life-world’ of the dying.<sup>25</sup>

At that point, an irrefutable understanding of personhood and human dignity had often ensued.

The following excerpts emphasize the powerful effect of these personal and family experiences:

*I think having had a lot of experience with family members, my father, my mother in hospice, my mother-in-law....it really does give you a different perspective as a health care provider if you have personally gone through it ...because you have **lived** it (Participant-2).*

*My dad passed away 2 years ago....and as hard as it was, he was the epitome of dying well. It was because... I chose to take the reins and talk to him about [his care]... And I told him what I knew. [After an invasive procedure] he said it 'hurt' and he said 'I hate it' and he was crying and I just took his hand and I looked him in the eye and I said, 'if you don't want to do it, it's OK.' I said, 'if you don't want to go any further with it,' and he said 'I don't. I said 'that's OK. That's what we need to know.' [My dad died at home] and like I tell not only my friends and family...my dad not only taught me how to live well but he taught me how to die well. So I had a very, very positive experience. And I think we're doing a tremendous disservice not to provide that same kind of care for all of our patients and families (Participant-9).*

One participant had had personal experience as a critically-ill cancer patient. Her experiences resulted in profound understanding regarding the influence of nursing care:

*I was in ICU... really sick...she put everything aside and kept me in the bed and did a total bed-bath, very gently...didn't feel the need to talk, didn't feel like she needed to coax something out of me...her face is completely in my head...so when I think of what I want to do [for] my patients, how I want to treat them, how I want them to feel, she is the picture...her face that day was very gentle...I saw how much she [wanted] to do the right thing for me. She knew what I needed and she knew what she needed to change at that moment to make that happen. It made me feel loved even though it wasn't that, you know. But that's the way it made me feel...like she was doing this job because she...wanted to care for me that day. So, when I went into nursing, my goal was to become an RN, but I wanted to treat patients the same way she had treated me (Participant-12).*

A number of participants agreed that receiving meaningful feedback from patients, families, or fellow staff members had been influential in validating their decisions and informing their ongoing end-of-life care practice. For example, one nurse in this study made a decision to honor a dying patient's human dignity by removing restraints. This nurse indicated that affirmation for doing the "right thing" had encouraged ongoing end-of-life care practices regarding matters of dignity:

*I felt like it was the right thing to do, but to me it reinforced that I was doing the right thing...the son reiterated that later on by actually coming back to the hospital after his father had expired to seek me out to say what that meant to his family to see those restraints come off...because they looked at them in such a negative connotation. And they didn't necessarily have the medical knowledge to say 'does he really need these anymore?' [Removing restraints] allowed them to get their father back somewhat (Participant-4).*

The narratives revealed that mentors and role models had influenced the practice of many participants. These mentors or role models had been inspirational because they possessed clinical expertise *and* understanding of compassionate care. Moreover, they freely offered their support:

*She [the physician] would come every evening after she had finished her rounds in the hospital and sit down... for about an hour and talk to them... I remember her well... talking with her patients and listening ... really sit there and just listen to them... which was an amazing experience (Participant-1).*

*He said 'we need to just...be here.' And so we sat for a good probably 30 to 40 minutes, we sat there with her...and I was kind of like, 'Oh my, should we not be doing something for her.' I finally said 'Should we do something?' and he said 'We **are**. We are here for her' and I was like, 'Oh...OK, I get it.' So from then on I...understood. He said, 'Sometimes you don't always have to do things...in order to be there' and so that was a big eye opening [for me] (Participant-11).*

Education or training programs had broadened the understanding of end-of-life care for each participant in this study. While some sought formal higher education to support their clinical efforts, others cited the value of shared learning within professional organizations and support groups. Nonetheless, participants underscored the vital need for professional education, training, and support to enhance hospital nurses' understanding of end-of-life care:

*I wish everybody had to go to ELNEC. I went to this course and it just all made sense... you realize that there's a lot more to your job than just...pushing a med...changing a brief and doing all these things. It's a...wealth of knowledge... I wish it was a required learning (Participant-8).*

Moreover, Participant 3 expressed a sentiment that was echoed by other nurses: "I think the more I learn, the more I realize I don't know. I really just know the tip of the iceberg."

### ***Cultivating Significant Insights***

As a result of their experiences with dying patients, participants cultivated numerous significant yet practical insights regarding end-of-life care. The texts resonated with rich and abundant examples of these insights. The words of the participants revealed a sense of clarity about dying and death, a focus on human dignity, and an evolving understanding of holistic end-of-life care.



Participants shared similar viewpoints regarding dying and death. Many participants expressed a deep appreciation regarding the certainty of death and noted that this understanding influenced their perceptions regarding priorities of care. For example, Participant 4 stated:

*“I think [end of life] is as important as the initial diagnosis. I really do....I don’t think you save everybody. Someday we will have a cure for cancer or a cure for something else...but the miracle pill is not out there, so...at this point as far as I know we all leave this world, so [end of life] should be an important aspect of [care].*

Other participants also pointed out the inevitability of death and its implications for nursing care:

*[Many nurses] get the orders... do, do, do, task, task, task... and [sometimes]...we are not going to be able to do anything for this patient...stop poking and prodding...we need to have the real talk of...this is life or death...we can make this a lot easier...I mean death is inevitable...how would you like to die? It’s [death] somebody’s last breath, the last thing that they do on earth and you’re [the nurse] with them or you’re helping them through it. What [is] more important than the way you die?(Participant-8)*

Although participants acknowledged the certainty of death they recognized that many uncertainties surrounded the dying experience. Some participants conveyed the understanding that issues surrounding dying and death cannot always be “fixed.” One of the nurses emphasized that she had come to understand the importance of staying with patients and families during times of uncertainty and turmoil:

*I think oftentimes as nurses, we try to fix things. We run and get a box of tissues and hand it to them we say, ‘it’s OK, don’t worry, everything’s going to be all right.’ Or we run and say let me go get the Chaplin. And so we leave them alone in the room crying...we can’t always fix everything and... it’s OK to let people cry or to be angry or to respond however they want (Participant-11).*

Other narratives revealed insights regarding human dignity and a focus on personhood. Moreover, the texts revealed that these insights regarding personhood often originated from a place of self-understanding and self-acceptance. Participants acknowledged that personal or family experiences with serious illness or death had influenced them and provided the impetus

for sincerely understanding the ideals of human dignity and personhood for others. Participant 4 said “death speaks to us as people” and noted that end-of-life nursing care involved offering support for “the human aspect.” Other participants offered similar commentary:

*Illness is personal. And [dying patients] should feel they're more than [a] case number or a medical record number (Participant 12).*

*I think anybody who is at end-of-life... [whether] it's cancer, or AIDS, or just old age needs to know that you still value them as a person despite the fact that they can't do what they used to do when they were younger(Participant 10).*

In addition to emphasizing the personhood and dignity of patients and family members, participants also conveyed an understanding of diverse insights that support holistic care. For instance, many nurses in this study emphasized the importance of non-judgmental acceptance of ‘the other’ and the value of respecting alternative perspectives of life. One participant expressed:

*There's a different perspective...the ability to leave it [personal perspective] at the door though and when you cross the threshold to just try and see it from the perspective of the people that you are taking care of... And you don't have to agree with it...but you've got to understand...that there's another language out there...what you're saying isn't necessarily the only way to say it. None of us know [patient-family] situation before coming into the hospital. We see a glimpse in time (Participant-4).*

Nurses in this study also came to understand the necessity of accepting and respecting families and including family members in the plan of care. One participant expressed appreciation regarding the role of family at end-of-life:

*I love the concept of families. I mean that's who we are. It defines who we are... and every family has its own culture... in my opinion, it's respecting that culture.... not trying to make families fit into our goals, but learning who they are and what their goals are... for each other, their loved ones...in the dying process, it's ever so important (Participant-1).*

The narratives revealed that participants came to an understanding regarding other essential aspects of physical, emotional, and spiritual dimensions that contribute to holistic care.

Examples of representative insights expressed by the participants follow in the quotations below:

Patient suffering: *People suffer in many different ways...usually at end of life we see the physical...the poor symptom management, type of suffering. They're short of breath, they're in pain, they're grimacing...even prior to that, you can see spiritual suffering and I don't think we often address that...oftentimes when we are treating patients for pain, a big component of that pain is due to their spiritual suffering...sometimes when we are treating their pain and we are not getting good pain management it's because they are suffering spiritually and that's impacting their pain (Participant-11).*

Physical aspects of care: *I think a lot of [families] get this 'Do not Resuscitate' order and think 'well nobody is going to do anything.' You still have to [be particularly attentive to physical needs] ... I think that the family knowing that you're not...forgetting about their family member just because they're dying [is comforting] (Participant-10).*

A deeper understanding of the diverse dimensions of end-of-life care allowed participants an opportunity to use their knowledge and experience to focus on patient-family needs. Thus participants redirected energies that had been previously consumed by personal struggle or was expended for inaccurate or inadequate outcomes toward accomplishing patient-family goals. For example, Participant 11 shared a narrative regarding her understanding of the value of simple presence during challenging or emotional end-of-life encounters. This participant revealed that while she previously had used her time to seek the help of other more experienced care providers rather than remaining present for such encounters, she now valued the opportunity to be present to dying patients:

*I just sat with her...then her family came in and they were delighted, because they felt that someone was with her...I told them she had a rough night and what had happened and they were so...relieved that someone was with her and she wasn't alone, and so I think for the family it was comforting, and for the patient it was comforting. It was also nice for me.*

Participant 7 noted that the understanding necessary to care for dying patients and their families is an “accumulated kind of thing.” Her narrative and the narratives of other participants suggested that multiple insights regarding end-of-life care generate an expansion of

understanding and sensitivity to the human condition that contributes to integrated nursing practice.

### **Transforming the Understanding of End-of-Life Care into Nursing Practice**

As participants' understanding of end-of-life care evolved, their approach to providing care was transformed. The texts revealed that this change initially resulted in various isolated occurrences of effective care outcomes. These isolated but positive experiences were often pivotal towards creating a deeper transformation in their approach to care of dying patients and their families. Yet as these experiences multiplied, the participants developed the necessary confidence and conviction to consistently do the "right things" for patients and their families. The essence of nursing care described by these participants entailed an integrated approach to practice and an emphasis on the individual personhood of each patient and family member. Although the experiences of the participants were unique, a number of common threads characterized the nurses who cultivated this integrated practice. The following sub-themes described these common threads: "Making Connections," "Respecting Choice," "Offering Meaningful Support and Care" and "Embracing the Work."

#### ***Making Connections***

When speaking of their end-of-life care experiences, participants emphasized the importance of making connections with patients and their families. One participant expressed that "connections are crucial." Other participants echoed this sentiment and noted that connections with patients and their families evolved through genuine interest and attention to the details about their lives and what was important to them. For example, Participant 5 shared the following comments:

*I'm just a very down to earth person...and I feel like I'm pretty genuine in the way I interact with people...I try to take time with them and talk to them about their lives...[for example] I found out about him[patient], even though he couldn't tell me anything because he was unconscious. But I*

*found out about his life and their life and what they had been doing for the last few years...you know, just all this little stuff...their story and consequently his story too, but it was more their story as a couple...[be]cause they were definitely a unit.*

Similar sentiments were also expressed by other nurses in this study:

*I can tell you about their families, I can tell you things they like to do...they've joked around with me...they open up and you know their inner-most lives. You get to know what they're feeling, how much pain they're in... and not [just] physical pain, but emotional pain and how afraid they are for their families... (Participant-10).*

Participants expressed that an interest in the stories of their patients' lives in conjunction with their genuine support of them fostered an ongoing relationship of trust. Moreover, once they came to know someone, this knowing was the foundation for genuine attention to human dignity and individualized care at the time of the patient's death. Participant 12 shared details in one of the narratives:

*I had a patient just recently who loved his little dog more than anything...any other on the face of the planet other than his wife. And the dog slept with him on the bed at home every night...we got permission to bring this little dog in...and for the two days before this man died, that little dog slept on his bed. And the night that he actually...started to pass away, the little dog moved from his feet up close to around his pillow, and I thought to myself, 'that's significant.' This dog is picking up that something's changing[and] if I didn't know by talking to the patient when he was able to talk to us that this was crucially important, then I may not have been able to get that little dog in there (Participant 12).*

The texts disclosed that these participants also took the time to connect with family members. They made the effort to know family members by name and they were attentive to how the dying experience affected them. Participants made it a point to express care for family members as well as for the patient:

*[I connect] everything....as much as I can possibly think of as I'm in that room. I purposely do it...I try to purposefully pay attention to what's going on in the room with them [loved ones]....Have they had a chance to take a shower? Are they staying around the clock because they know the person is dying and they want to be there? I like to know...is it important for them to be there or are they afraid to be there?(Participant-12).*

In addition to efforts to connect with patients and their families, participants also called attention to other important connections. For instance, relationships among interdisciplinary team members were highlighted as being particularly important. Participant 3 emphasized the necessity of these professional connections and noted that equal voice and open collaboration

among team members was essential to ensure that the patient remained at the “center” of care. Nonetheless, this participant as well as other nurses in the study emphasized a vital aspect of transforming their “connections” into meaningful care – that of respecting patient and family choice.

### ***Respecting Choice***

The texts highlighted the necessity of learning about patient and family wishes and respecting their choices for care options. Participants emphasized the importance of listening in order to discern these important understandings. One participant noted that “they will teach you what is important to them if you listen.” Participants learned that people want to be heard. Another participant pointed out, “they are not expressing a need just to say it. They are telling you because it means something to them.” Participant 1 suggested that by taking the time to listen, her needs for “expert certainty” or “control” over care were not necessary. She further admitted, “their [patient and family] goals become my goals.”

Participants disclosed that they advocated for patient-family wishes and they emphasized the vitality of Advanced Directives. Participant 4 referred to Advanced Directives as the “important conversation” and noted that active engagement in this conversation was necessary for all people in American society. Other participants echoed similar or related sentiments regarding honoring patient and family options for care. Several examples are noted below:

*Sometimes patients and their families do not know what the alternatives are. It is important that they know their options and what to expect so that they can make informed choices (Participant-9).*

*We have our own perception of what would be a good death... and what my idea of a good death is going to be very different from someone else's...it took me a while to realize everyone wouldn't want to be dying the way I would. And so I think that's...that's important to know... sometimes it's hard allowing people to make choices that we ourselves would not necessarily want. But that's what you have to do in nursing (Participant-11).*

The texts revealed that the nurses in this study frequently complemented patient and family knowledge with professional knowledge. However, participants always supported and advocated for them to make their own decisions. Moreover, participants remained cognizant of ethical and professional guidelines and they recognized that honoring patient and family choice was a delicate balance. They also recognized that vigilance was needed in order to respect professional boundaries so that personal biases would not be imposed upon patients or standard of care be breached.

Participant 12 highlighted yet another understanding about patient choice when she underscored the importance of what she referred to as the “emotional directive.” This participant expressed details about this aspect of end-of-life care:

*[Professionals] talk about advance directives and what a person wants at the end of life for physical care and treatment, but they are only thinking about medical procedures. Most professionals are not thinking about what is really important to the patient on an emotional level.*

Meaningful experiences for this participant involved care that respected patients’ choices for emotional well-being with the same emphasis that is given to respecting choices for physical well-being. This nurse conveyed a vital understanding about respecting choices and honoring an individual’s human dignity:

*I have not done my job and I will not come home feeling like I’ve done the right thing by a patient whose just passed away if I had not done all the things that I know are important to that [individual] patient.*

### ***Offering Meaningful Support and Care***

When participants attended to knowing patients and their families and discerning their wishes for end-of-life, these details became the foundation for offering meaningful support and care. Although actions to provide support and care were as diverse as the patients and families themselves, one common essence was evident – meaningful actions were individualized to address the unique needs and circumstances of each person.



All of the nurses in this study emphasized the importance of addressing symptom management. They recognized that relief of physical suffering was a priority for patients at end-of-life. In a narrative regarding a terminally-ill patient with complex wound care, one participant conveyed the urgency of alleviating physical distress:

*She was in the type of pain that people worry about... I told [interdisciplinary team], 'we are not doing right by her...we need to get the pain under control' and I said 'This is not what is best for her. She is not comfortable...she is going to die within the next couple of days.' So we did a lot of different things to make her comfortable...changed the type of dressings that were being done that were extremely painful...put her on a lot more pain medicine...that kind of thing (Participant-12).*

In addition to relieving physical distress, the texts revealed that the participants offered support in many other ways. For example, several participants emphasized the vitality of communicating presence, care, and acceptance.

*I think being present means you are just there...you are not tidying up the room, you're not assessing [the patient], you are not fixing the linens, or turning [the patient], or you are not doing anything to [the patient], but you are just being there...sometimes I will just sit and hold [the patient's] hand, or rub their hair, or just be with them...because I think people sense presence (Participant-11).*

*I think they do sense my deep feeling. It helps [them] get out where they are at their deepest, blackest hole, and helps them rise a little bit...and then they are able to process and make decisions [for themselves] (Participant-1).*

*One of the most important things... is to sit down when you go into these rooms. Sit down. Even if you sit down for 4 minutes, the perception is that you've sat for a lot longer...that's something I do... I immediately look people in the eye, I hold their hands and I say, 'How are you? Are you ok? What can I do for you?' and really just translate that I **do** care and I want to know (Participant-6).*

*She got to trust us I think...she saw the things we did for him...little [things]...like when I turned him, I'd brush his hair a little bit, so he didn't look like a mess...little stuff that showed caring, and not to be afraid (Participant-5).*

Still other participants emphasized the value of responding honestly and compassionately to difficult psycho-social or existential issues:

*They were just in tears...I could hear anger, so I went out and interrupted and brought them into [quiet place] and sat down and talked with them, and really just listened to them. They went back to the past [about] him, and what he was like and who he was. I really sat and listened to them for about an hour...and so we talked about that...and how he was comfortable.... At some point he would die, he was not going to get better outside of a miracle. They agreed with that and accepted it and then we talked about where he would go from there. And so in that length of time they went from the anger and they talked. By the time they left, they were at peace. They were kind of laughing and telling stories about him (Participant-1).*



*I listen...and there's something that they say to me that tells me that this is an opening,[respond] to this. For every patient it's something different...I had a patient who once said to me, 'When is this going to end?' And that was the opening for me to say, 'What do you want? What do you mean end?' I'll be [honest]. But I have to have that opening... it's different for everyone. There are [some] people who have never given it to me (Participant-10).*

The texts indicated that individualized patient and family education was a priority at end-of-life. Participants noted that confronting dying and death was an uncommon experience for most people in American society. Education often assuaged anxieties associated with the unknown, aided in decision-making processes, or facilitated engagement in the plan of care. Participants agreed that the most effective education was grounded in an understanding of patients and their families.

*You're saying... 'what your mom is going through right now is called this, it's perfectly normal. This is why this is.' I mean....if you can teach this...people [families] don't panic and they are more at ease...of sitting there closer. So if you can explain things, I think the patient gets the close...support that they need. I think that's where they get the strength (Participant-6).*

*Education [is important] for a situation like the husband and the wife...where she wants one thing and he is really adamantly against it and is being very verbal about it. Is it because he's really against it or is it because he doesn't understand it? So you take the layers apart and educate him that this [decision] is really what she wants and find out...is it a fear or is it just a lack of knowledge? [Does] he think by doing this, he's going to hurt her? Different people have different [understandings]. You don't know how he's thinking until you start the education process (Participant-12).*

Supportive actions such as removing barriers to personalized care, creating comforting personal environments in the hospital setting, and supporting a person's individual expressions of spirituality were likewise often described by the participants:

*Restraints and IV tubing and needles and things seem to hold families back... Side rails also hold families back [if] the patient is not moving....So one of the things I did and I still continue to do is lower the side rail nearest to the spouse or whoever it is that is taking the seat right next to the bed.....so they can just reach out and touch [the patient] (Participant-4).*

*Does [patient] have favorite pictures? Bring them in. Does [patient] have a favorite blanket? Bring it in. Bring in anything...within [reason] because if you're going to die in a hospital, do you really want to feel like you're in this hospital bed? No, most people probably would prefer to be in their own bedroom...but it doesn't look or feel like a bedroom, so bring [belongings] that would make it more personable to that person (Participant-12).*

*I'll pray with patients...if I get the sense that they're a religiously-based person. [Pastoral care] can come and talk to them about whatever it is they want to talk about. Those are really important things for people to feel like they've...tied some loose ends up or made some reconciliation, and to feel like that they have done everything that they could do there at the end. If I see somebody needs*

*that or is talking about that, or they're wearing [religious symbol] that tells me something about them. If somebody is dying and that [religion or spirituality] is a part of their life, [then] that is something that I should also address (Participant-5).*

Whereas the above quotations point out representative supportive and caring practices, the participants in this study shared numerous other examples of support and care. Among these examples, the participants often offered support to families in carrying out rituals and gatherings to honor the life-story of the dying person. These rituals honored the dignity and personhood of both patients and their families. Participant 5 described an example of a family celebration and she emphasized that it was a positive end-of-life experience:

*He [brother] brought his keyboard up there and they were down there playing music for her and singing....I felt like I did something very good. I got her family all together there and made it as wonderful as possible...almost kind of like a party....a celebration. OK, you [have] three hours left to be with your sister, it's like take the opportunity and whoever wants to be there, be there with her and play music and do things that make you happy. She died that afternoon and [the] family was all with her. That was...a good thing (Participant-5).*

### ***Embracing the Work***

The texts underscored another important sub-theme regarding end-of-life care. Participants embraced their work with dying patients and their families. When participants placed the focus of nursing care upon matters of human dignity and compassion in addition to scientific knowledge and skill, they became more effective in achieving meaningful care outcomes. Personal fulfillment and job satisfaction were cultivated because of these ideals. Words such as “gratitude,” “gift,” “love,” “intimacy” or “grace” were often used to describe their nursing care experiences. Although these ideals were common threads within many participants’ narratives, the words of the following individuals bear witness to this important detail of end-of-life care:

*It's such an intimate thing to be with these people during that time in their life...if the person is open enough to talk with me and trust me, that's a very big thing...to have somebody trust you and to form those relationships with people. I wish everybody could give the kind of care that we give (Participant 5).*

*I have turned to many patients and I say to them, 'thank you for letting me be part of this.' I mean that's a pretty private moment when a loved one is dying and [the nurse] is asked to be a part of it. I always thank them. It is the most rewarding, unbelievably moving experience to be with the family and the patient [who is] dying. I've seen babies being born, but that moment when [a person at end-of-life] dies...if everything is right...if they are not in pain, if the family knows what's coming...It is an unbelievable [positive] experience (Participant-6).*

## **Summary of Research Findings**

The texts revealed that participants were confronted with numerous and diverse challenges when providing care for dying patients and their families in the hospital setting. These challenges often caused the participants to struggle and their struggles were frequently associated with intense emotional consequences. Participants who grew in their understanding of human dimensions of care experienced multiple insights that guided their end-of-life nursing practice. As their professional experiences and understanding accumulated, the participants manifested a tangible end-of-life practice reflecting an integrated approach to their nursing care. This integrated nursing care manifested in a commitment to assist hospitalized terminally-ill patients in "dying well" or "dying peacefully." Participants advocated holistic care and its practice, the inclusion of families in care planning, and non-judgmental approaches to patient-family choice. They also intently valued the personhood of each of their patients and they were champions for patient-family education in alternatives of care and treatment. The participants emphasized that their focus on the uniqueness of each person made it possible to sincerely honor human dignity for patients and their families at the time of their dying and death. Attention to these matters resulted in the most meaningful nursing care experiences for participants themselves.

## **Methodological Rigor**

Hermeneutic inquiry recognizes multiple and different interpretations of a phenomenological experience. However, standards of rigor are necessary to facilitate achievement of excellence. Sandelowski's<sup>28</sup> four criteria for achieving rigor include truth value, applicability, consistency, and neutrality. These criteria are particularly relevant for merging the

“scientific rules and artistic imagination” that are germane to nursing.<sup>28 (p32)</sup> Thus, the investigator maintained attentiveness to these criteria throughout the conduct of the study.

*Truth value*, which resides in the lived experience, was assured by seeking descriptions from participants who had actual experiences of providing end-of-life care in the hospital environment. Active engagement by the investigator with the participants and use of in-depth audio-taped interviews and verbatim transcriptions assured that their perspectives were represented as clearly and genuinely as possible. Moreover, the identification of assumptions and personal pre-understandings assured that the investigator recognized the influence of personal perspectives when interpreting the data. For example, the investigator remained aware of her bias regarding psycho-spiritual care of dying patients and their families and was attentive to its possible influence on the interpretation of participants’ narratives.

A study meets the criterion of *applicability* when the findings authentically “fit” the data from which they are derived and are representative of the participant’s life experiences.<sup>28(p32)</sup> The essential themes regarding end-of-life care were grounded in verbatim quotations from participants. This grounding in the data supported the applicability of the study findings. Peer debriefing and “hermeneutic conversations” with two nurse experts in the fields of hospital and end-of-life care facilitated authenticity of interpretations regarding the experiences.<sup>6(p100)</sup> Regular collaborative meetings with experts in phenomenological methods also provided the opportunity for considering investigator assumptions and pre-understandings and for ensuring that the study findings were applicable to the participants’ lived experiences.

An auditable decision trail was maintained in order to address the criterion of *consistency*. A log of methodological decisions was maintained throughout the study. Research

materials from all phases of the study were preserved and audited including transcripts, field notes, reflective notes, and interim interpretations and summaries.

*Confirmability* of the findings is the hallmark of *neutrality*. Sandelowski<sup>28,29</sup> suggested that attainment of confirmability depends on a faithful and orchestrated adherence to the chosen methodological approach. The investigator carefully adhered to van Manen's<sup>6</sup> methods and this action helped to ensure that the process remained logical and methodologically congruent throughout the study.

### **Study Limitations**

Although the investigator sought to obtain a sample representing maximum variation among participants, the majority of participants were Caucasian and female. This is a limitation because a significant number of nurses who work in inpatient clinical units in this country are from a range of ethnic backgrounds or are males. Thus, a study in which participants are recruited based on gender and ethnic or racial characteristics would better represent the experiences of all nurses providing end-of-life care in the hospital setting. Nevertheless, the findings of this study are significant to end-of-life nursing care practice.

### **Discussion of Research Findings**

Participants in this study identified numerous and multi-faceted end-of-life challenges in their day-to-day professional care-giving role. Prior research studies focusing on end-of-life recommendations, perceptions, or experiences of hospital nurses likewise cited similar care challenges.<sup>15,17,22,24,30-36</sup> Findings of several studies highlighted nurses' experiences regarding complex psychosocial and spiritual patient care issues.<sup>23,24,30,34-36</sup> Other studies shed light on nurses' perceptions of obstacles to effective end-of-life care in particular clinical settings, such as in oncology or ICU.<sup>17,31-33</sup> The findings of this investigation were comparable to the findings of

previous research studies highlighting the disappointing persistence of such issues despite significant efforts and recent advancements in palliative care in this country.

The findings of this study also underscored the importance of interpersonal skills such as deep listening and effective communication. These skill-sets formed the underpinnings for support of patient choice and for respect of what was most important to patients at the time of their dying. Prior nurse researchers have also identified the need to improve active listening and other vital communication skills.<sup>37-39</sup> In cited studies, recommendations have been made for hospital nurses to foster meaningful relationships with patients and their families. These relationships have been described as vital to better gauge the manner and level of psycho-social involvement needed during the illness and dying trajectories.<sup>39</sup>

This study also highlighted emotional consequences of end-of-life care upon the hospital nurse. Prior nursing research studies and reports identified emotional effects of caring for terminally-ill hospitalized patients.<sup>15,22,40,41</sup> Frustration, suffering, and grieving were reported in these studies and similar findings were noted in this investigation, as well. The findings of previous investigations suggested that nurses often rely on personal coping strategies to deal with complex issues and many participants in this study used similar strategies. Short-term personal coping strategies are certainly worthwhile for maintaining a professional demeanor in the clinical setting. However, long-term consequences such as attitudes of indifference can result if clinical processes are not in place to support hospital nursing staff to deal with intense emotional responses related to dying and death.<sup>40</sup> The risk of negative consequences for nursing and other hospital staff is greater when the circumstances of a patient's dying are unexpected, tragic, or occurs as a result of an adverse event.<sup>15,42,43</sup> The risk for negative consequences is also greater if

the nurse is not well-prepared to deal with the complexities and uncertainties of dying and death.<sup>5</sup>

Moral distress is another long-term consequence associated with nursing care.<sup>44,45</sup> Nurses who face relentless or unresolved end-of-life struggles have a greater possibility for developing moral distress.<sup>22,44</sup> Findings of prior nursing studies have suggested that morally-distressing end-of-life care shares a significant association with the experience of emotional exhaustion for some nurses.<sup>45</sup> Some of the participants in this study also experienced emotional exhaustion. Circumstances that result in relentless physical and emotional exhaustion are concerning for the nursing profession because exhaustion is a key component of nurse burnout and staff turnover.<sup>15</sup> Regrettably, nurse burnout and staff turnover can lead to inconsistencies in care processes and poor quality outcomes for terminally-ill patients and their families. Effective care for these patients depends on the availability of nurses who are not emotionally or physically compromised.

As previously noted in this study, the participants indicated that education and training strategies had provided meaningful insights regarding end-of-life care. These findings are consistent with previous nursing reports regarding education, training, and experience.<sup>8,14,20,21,46</sup> In spite of these findings, strategic plans for acute care hospitals are generally focused on science, technology, and cure for the living. For this and other reasons such as cost containment, educational and training resources for end-of-life are often not a priority for administrators and other hospital leaders.

The most encouraging findings of this study were included in texts provided by confident, qualified nurses who worked in palliative care or other nursing care settings where end-of-life standards were supported or promoted. The texts describing care that coupled

scientific knowledge and skills with an understanding of human dimensions were consistent with ideals outlined in the NCP<sup>12</sup> guidelines and with ideals of nursing praxis.<sup>47</sup> Moreover, the accounts of nurses' work with terminally-ill patients and their families were described in a manner consistent with professional competence and autonomy, ethical-moral certainty, empowerment, and genuine personal fulfillment.

### **Recommendations**

Nurses have an important role in caring for dying patients and their families. Altogether these findings underscore the need for continuing professional emphasis on end-of-life care in the hospital setting. A number of recommendations based on the findings of this study are relevant for nursing practice, nursing education, and future research.

#### **Recommendations for Practice**

The participants highlighted the importance of professional development currently available within end-of-life education and training programs. For this reason, these findings support an ongoing emphasis on end-of-life nursing education in all settings where care is provided for all patients who die. Although many contemporary hospitals consider participation in ELNEC<sup>13</sup> and other similar programs a voluntary endeavor, greater emphasis on this level of education is needed if the NCP<sup>12</sup> vision is to be realized for all hospitalized patients.

#### **Recommendations for Nursing Education**

These findings suggest a need to better prepare nurses early in their careers for providing end-of-life care. An emphasis on appreciation for human dignity is needed from the first day of nursing school as well as strategies to guide students in patient and family-centered caring practices at the end of life.<sup>12</sup> Furthermore, an increase in the frequency and extensiveness in



clinical practice of human-to-human relating is necessary. Use of carefully-crafted simulated experiences may be helpful in providing meaningful preparation.

### **Recommendations for Future Research**

Further research is needed to explore the end-of-life care experiences of men and nurses from diverse ethnic backgrounds. Also needed is additional study of the experiences of providing end-of-life care by nurses who have not had the benefit of end-of-life training or education. Quantification of the outcomes and benefits of care provided by nurses who have participated in ELNEC or other similar end-of-life education programs needs to be undertaken. Additionally, research is needed in inpatient clinical settings to quantify the root causes and degree of nurses' emotional and physical exhaustions and their influence on end-of-life care and its outcomes.

### **Conclusion**

Stories of hospital care typically focus on treatment and cure. This investigation provided findings regarding end-of-life nursing care in the hospital setting. In this study, the interviews of 13 hospital nurses from diverse inpatient clinical settings provided data that offered a deeper understanding of care for terminally-ill patients and their families. Three key themes emerged from this inquiry. These themes described common challenges and struggles, evolving understandings regarding end-of-life care, and an integrated patient and family-centered end-of-life nursing care approach. Common threads across all three themes included the preservation of human dignity and a focus on human dimensions of care. Salient recommendations for nursing practice, education, and research focus on expansion of training in holistic caring approaches.

**Table 1.0: Demographic Characteristics of Study Sample (n = 13)**

<b>Age Range:</b>	
25-35	1
36-45	4
46-55	7
>55	1
<b>Gender:</b>	
Male	1
Female	12
<b>Ethnicity:</b>	
African-American	0
Caucasian	11
Hispanic	1
Pacific Island-Asian	1
<b>Employment Setting:</b>	
Academic Medical Center	10
Community Hospital	3
<b>Clinical Work Setting:</b>	
Palliative Care	4
Med-Surg/Oncology	5
Critical Care/Progressive	3
Float Pool	1
<b>Education Level:</b>	
Associate Degree	4
Bachelor's Degree	6
Master's Degree	3
<b>End-of-Life Training</b>	
ELNEC	11
Other	2

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UNDERSTANDING NURSES' EXPERIENCES OF PROVIDING END-OF-LIFE CARE IN  
THE UNITED STATES HOSPITAL SETTING

Appendices: Institutional Review Board Submission and Approval

Appendix A – VCU Research Plan

Appendix B – Recruitment Script

Appendix C – Interview Questions

Appendix D – Demographic Form

Appendix E – IRB Approval of Research Study

## Appendix A

Rev. Date: 7-15-08

### VCU RESEARCH PLAN TEMPLATE

Use of this template is required to provide your VCU Research Plan to the IRB. Your responses should be written in terms for the non-scientist to understand. If a detailed research protocol (e.g., sponsor’s protocol) exists, you may reference that protocol. **NOTE: If that protocol does not address all of the issues outlined in each Section Heading, you must address the remaining issues in this Plan. It is NOT acceptable to reference a research funding proposal.**

**ALL Sections of the Human Subjects Instructions must be completed with the exception of the Section entitled “Special Consent Provisions.”** Complete that Section if applicable. When other Sections are not applicable, list the Section Heading and indicate “N/A.”

**NOTE: The Research Plan is required with ALL submissions and MUST follow the template, and include version number or date, and page numbers.**

### **DO NOT DELETE SECTION HEADINGS OR THE INSTRUCTIONS.**

#### **I. TITLE**

“Understanding Nurses’ Experiences of Providing End-of-Life Care”

#### **II. STAFFING**

**A. In the table below (add additional rows as needed), indicate: (1) key project personnel including the principal investigator and individuals from other institutions, (2) their qualifications, and (3) a brief description of their responsibilities.**

NAME OF INDIVIDUAL	QUALIFICATIONS	RESPONSIBILITIES
D. Patricia Gray	PhD, RN	Principal Investigator (responsible for research and will serve as primary contact)
Susan C. Johnson	RN, MS	Student Researcher

**B. Describe the process that you will use to ensure that all persons assisting with the research are adequately informed about the protocol and their research-related duties and functions.**

The Student Researcher (Susan C. Johnson) has completed all requisites for doctoral course work including research courses. She has completed the required Human Subjects Protection training. She has received individual mentoring in the conduct of qualitative inquiry. She was involved in every aspect of development of the research protocol. She will coordinate subject recruitment and will conduct all research interviews and analysis. The study procedures for



ongoing and regular oversight of the student researcher’s work are described in the section on rigor (see below).

If interviews are professionally transcribed, the transcriptionist will have completed human subjects training and will be required to sign a confidentiality statement.

### III. CONFLICT OF INTEREST

**Describe how the principal researchers and sub/co-researchers might benefit from the subject’s participation in this project or completion of the project in general. Do not describe (1) academic recognition such as publications or (2) grant or contract based support of VCU salary commensurate with the professional effort required for the conduct of the project**

The researchers will not benefit from subjects’ participation or completion of this project.

### IV. RESOURCES

**Briefly describe the resources committed to this project including: (1) time available to conduct and complete the research, (2) facilities where you will conduct the research, (3) availability of medical or psychological resources that participants might require as a consequence of the research (if applicable), and (4) financial support.**

1. The student researcher is available to focus exclusively on the conduct of this study.
2. Each participant interview will be conducted at an accessible location that is selected by the participant. Data analysis will be completed at the School of Nursing and in the student researcher’s home.
3. This research presents no more than minimal risk to participants. If participants become emotionally upset during the interview they will be encouraged to seek support from minister, counselor, or other appropriate person and participant will be informed that this support will not be at cost to the project.
4. No financial support is available nor required to complete this study.

### V. HYPOTHESIS

**Briefly state the problem, background, importance of the research, and goals of the proposed project.**

A hermeneutic phenomenological design will be used to develop an understanding of nurses’ experiences in providing end-of-life care; therefore, research hypotheses are not appropriate. The research question to be addressed is: “Among nurses who provide end-of-life care for adults in inpatient hospital settings, what are their understandings of those experiences?”

This research is important because of the growing number of people in the United States who are expected to die in inpatient hospital settings over the next 30-40 years. As care providers, nurses are likely to be in a position to significantly influence the quality of end-of-life care. Numerous researchers and clinicians have recommended that systematic exploration take place into actual experiences and reflections of nurses who care for terminally-ill patients

and their families. Resulting data will be a reliable source from which to build support for continued advancement of compassionate and holistic palliative care (Calvin, 2007; Ferrand et al., 2003; Ferrell & Coyle, 2008).

## VI. SPECIFIC AIMS

The proposed study will address the following specific aims:

- Develop an understanding of the contextual background for each participant’s original and ongoing views on end-of-life care;
- Develop an understanding of nurses’ experiences in end-of-life care.
- Examine findings for implications related to knowledge development and practice innovation.

## VII. BACKGROUND AND SIGNIFICANCE

**Include information regarding pre-clinical and early human studies. Attach appropriate citations.**

As early as 1965, significant issues surrounding awareness of dying and the quality of dying and death in western society had been described (Glaser & Strauss, 1965). At that time, in spite of public and professional concern about the appropriate use of life-extending technology and mounting evidence regarding the anguish associated with terminal illness, there was little visible interest or support by the health care community to address this complex phenomenon. During the 1980’s two important initiatives offered the promise of dignity and quality care for terminally ill patients. The first was the introduction and advancement of the hospice movement in this country. Hospice care offered an alternative to the highly technical, depersonalized approach that had become dominant in the western health care system (Kastenbaum, 2001). The second was the initiation in this country of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT, 1995) accompanied by its companion research efforts (Phillips, Hamel, Covinsky & Lynn, 2000). However, it was not until 1995 that the results of the SUPPORT study were published, revealing major deficiencies and inefficiencies in end-of-life care.

Subsequently, the Institute of Medicine (IOM) developed and disseminated a landmark publication entitled *Approaching Death: Improving Care at the End of Life* in order to reform end-of-life care (Phillips, Hamel, Covinsky & Lynn, 2000). A major goal of the IOM was to stimulate constructive health system change by “strengthening popular and professional understanding of what constitutes good care at the end of life and by encouraging a wider social commitment to caring well for people as they die” (Field & Cassel, 1997, p. 1). Funding provided by the National Institutes of Health (NIH) and other major organizations, such as the Robert Wood Johnson Foundation (RWJF), stimulated additional interest for research and health care improvement in the area of end-of-life care. Since publication of the SUPPORT study and IOM report, considerable resources and effort have been expended by an array of professional disciplines to resolve the gaps in end-of-life care (SUPPORT, 1995; Field & Cassel, 1997). The findings of recent research studies have contributed significantly to the

development and dissemination of interdisciplinary palliative care guidelines (Ferrell et. al., 2007a).

### ***End of Life Nursing Education – Dissemination of Standards***

In 1997, a mandate was promulgated by the International Council of Nurses to establish that end-of-life care and the promotion of peaceful death was a priority for nursing (American Association of Colleges of Nursing, 2004). Shortly thereafter, core nursing competency statements related to end-of-life care were developed through the efforts of nationally recognized palliative care experts (ELNEC, 2008). These competency statements were reflected in the 1998 publication disseminated by the American Association of Colleges of Nursing (AACN) entitled *Peaceful Death: Recommended Competencies and Curricular Guidelines for End of Life Nursing Care*. Moreover, the End of Life Nursing Education Consortium (ELNEC) project, a national education initiative reflecting the AACN guidelines, was funded during 2000 by a major grant from the RWJF. ELNEC is a well-recognized formal educational program which uses a highly developed curriculum to address end-of-life standards; it affords nurses the specialized training needed to provide comprehensive quality care to patients and families facing terminal illness (ELNEC, 2008). The original core curriculum has undergone further development in order to address needs of diverse nursing care settings, such as critical care, geriatrics, and pediatrics. Curriculum content consists of principles of palliative care, pain and symptom management, loss and bereavement and ethical issues. While the content is geared toward the particular nursing care setting, universal themes are threaded throughout all setting-specific curricula (Sherman, Matzo, Pitorak, Ferrell & Malloy, 2005). These universal themes include the significance of the family as unit of care, role of nurse as advocate, cultural and spiritual influences, attention to special populations, critical financial issues, and interdisciplinary care team. The ELNEC curriculum has been disseminated both nationally and internationally and has received consistent positive evaluations (Coyne et al., 2007; Ferrell et al., 2005; Ferrell, Virani, & Malloy, 2006; Ferrell et al., 2007b; Kelly et al., 2008; Malloy et al., 2006; Malloy et al., 2007; Paice, Ferrell, Coyle, Coyne & Callaway, 2008). To date, over 4,750 practicing nurses have benefited from ELNEC training (ELNEC, 2008). Moreover, since the dissemination of the original ELNEC curriculum, other formal, comprehensive, and setting specific end-of-life educational endeavors based on palliative care standards have been initiated.

### **Summary and Implications of Literature Review**

The international and national health care communities have risen to accept the challenge to improve care and service at the end of life. As a result of efforts to advance quality in this field of care, educational and clinical standards have been developed and disseminated. Chinn and Kramer (2004) contended that genuine knowledge for a practice discipline depends on *integrating* scientific, ethical, aesthetic, and personal aspects of knowing. They further suggested that reflection, as well as sharing of knowledge and experience, create a “disciplinary community beyond the isolation of individual practice” (p. 3). Thus, current knowledge regarding end-of-life care would be enhanced by giving voice to nurses’ experiences.

## **VIII. PRELIMINARY PROGRESS/DATA REPORT**

If available.

NA

#### **IX. RESEARCH METHOD AND DESIGN**

**Include a brief description of the project design including the setting in which the research will be conducted and procedures. If applicable, include a description of procedures being performed already for diagnostic or treatment purposes.**

A hermeneutic phenomenological research design will be used. The research methods outlined by van Manen (1990, 2001) will be employed during the conduct of this study.

Up to 15 registered nurses (RN) will participate in this study. Inclusion criteria for the study will consist of the following: 1) being currently employed as an RN within an adult inpatient clinical care area, in either an academic or community hospital setting; 2) understand, read and speak English; 3) having completed a comprehensive end-of-life education program or training curriculum, such as ELNEC; and 4) having end-of-life patient care experience after completion of the end-of-life training.

Recruitment of potential participants will be accomplished through posting of an information flyer about the study in nurse-accessible locations within VCU Health System’s inpatient areas, as well as distribution of information about the study to professional contacts, community-based coordinators for ELNEC training, and other community-based nurse leaders with professional interest in end-of-life care who are willing to share the information with nurses employed in adult inpatient clinical care settings. ***(A copy of the recruitment information flyer is attached to this document)***. Additionally, the researcher will distribute information about the study to leaders of local chapters of professional organizations, such as the Richmond chapter of the Oncology Nursing Society and the Richmond area chapter of American Association of Critical Care Nurses. Those interested in participating in the study or who may have questions about the study will be asked to contact the researcher directly to ascertain whether inclusion criteria are met and complete the informed consent process ***(A copy of the recruitment narrative is attached to this document)***.

Data collection will occur over a 3- to 4-month period and a variety of methods will be used to generate the data for this study. Participant demographic data forms will be used to obtain information for describing the study sample. ***(A copy of the demographic data form is attached to this document)***. Data regarding nurse experiences will be acquired through semi-structured in-depth audio-taped personal interviews with study participants. ***(A copy of interview questions is attached to this document)***. Additional data will be obtained through researcher field notes and personal reflexive journaling. These multiple sources of data will allow the researcher to explore and clarify emerging themes.

During semi-structured face-to-face interviews conducted by the researcher, participants will be asked to share thoughts, feelings, reflections and meaningful experiences in providing end-of-life care for patients or their families. Additional questions may be posed in order to explore context and meaning of the reflections, experiences, or comments that are verbalized. Each interview is expected to last up to 60 minutes, depending on details of the responses. Each interview will be audio-recorded with consent of the participant. During the interview, the researcher will make brief and inconspicuous field notes to identify key concepts or note significant observations regarding behaviors, facial expressions, and expression of emotions. Additional field notes will be recorded by the researcher immediately after the interview in

order to explicate behavior or a meaningful recounting, to note impressions, or to place data in context. Field notes will be completed in order to assist the researcher to accurately consider and interpret the particular events and recounting of the interview. Permission will be obtained from each participant to contact him/her again if there is a need for clarification of any information obtained in the interview session.

In addition to interview data and field notes, the researcher will maintain a personal research journal. This journal will include personal assumptions and biases, reflections on personal experiences and insights, as well as notes regarding methods and decisions. Journaling is intended to heighten attentiveness to self and others, enhance understanding and interpretation of the phenomenon under study, as well as facilitate an audit process of study methods and decisions (Mackey, 2007; Munhall, 2007).

Data collection and analysis will proceed using an iterative process and participants will be recruited until data saturation has been achieved or until a sample of 15 participants is reached, whichever comes first.

#### **X. PLAN FOR CONTROL OF INVESTIGATIONAL DRUGS (If the VCUHS Investigational Drug Pharmacy is not used), DEVICES, AND BIOLOGICS**

**Describe your plans for the control of investigational products including: (1) how you will maintain records of the product’s delivery to the trial site, the inventory at the site, the use by each subject, and the return to the sponsor or alternative disposition of unused product(s); (2) plan for storing the investigational product(s) as specified by the sponsor (if any) and in accordance with applicable regulatory requirements; (3) plan for ensuring that the investigational product(s) are used only in accordance with the approved protocol; and (4) how you will ensure that each subject understands the correct use of the investigational product(s) (if applicable) and check that each subject is following the instructions properly (on an ongoing basis).**

NA

#### **XI. DATA ANALYSIS PLAN**

**For investigator-initiated studies.**

Demographic data will be summarized, and information will be used to describe characteristics of the study sample in written research reports. Audio recordings of participant interviews will be transcribed into text format by the researcher or a transcriptionist who has completed human subjects’ protection training. Transcribed text will serve as the data for analysis, along with field notes and personal reflection journal. Data will be analyzed according to the methods and procedures outlined by van Manen (1990, 2001). Key steps in the process are as follows:

- Assume a phenomenological style of thinking and orienting; that is, outline personal assumptions and pre-understandings and adopt an attitude of reflective attention to lived experience.
- Conduct audio-taped interviews to obtain experiential narrative descriptions from the participants as a resource for developing understanding of the phenomenon.
- Transcribe the interviews into text; read each interview while listening to the

audio-tape in order to validate accurate transcription of data.

- Use a coding procedure to enable identification of text that is relevant to the phenomenon of interest; material that is irrelevant is deleted from the working document.
- Conduct reflective thematic analysis of each interview; that is, uncover essential thematic aspects in each narrative text by (1) multiple readings and reflection on the text in its entirety, (2) selective reading of text for significant statements and phrases, and (3) detailed line-by-line reflective examination of the text. Field notes, journal entries, and related literature are used as data to increase insight.
- Interpret meanings within the text data by using an iterative reflective process of reading and reflection, considering parts and whole (hermeneutic spiral).
- Read text *across* participant interviews to confirm common essential themes and shared meanings.
- Communicate an interpretive understanding of the phenomenon in the writing of a phenomenological narrative. The ending anecdotal narrative reflects many different stories of meaning, while outlining similarities and differences, as well as common patterns, themes and discoveries.

Methodological Rigor: A number of steps will be used to ensure rigor of both study processes and study outcomes. An audit process will be implemented throughout the study to ensure adherence to van Manen’s (1990) method. Ongoing meetings with dissertation advisor and committee will be conducted in order to review study progress, discuss issues and concerns that may arise during data collection or analysis, discuss relevant entries in reflexive journal, review interpretations of interview data, and ensure adherence to standards of rigor. Peer debriefing (using de-identified data) will be completed during data analysis and interpretation phases with a minimum of two to three selected professional nursing colleagues who have extensive expertise in nursing and/or end-of-life care. Peer debriefing will provide the opportunity for ongoing response and feedback regarding interpretation of data and unforeseen presence or consequences of assumptions.

Limitations of the Study: This is a qualitative research study; therefore, the findings are not intended to be generalizable. The understandings derived from this study will be based on experiences of registered nurses who have completed end-of-life care training and who are professionally employed to provide care for patients in inpatient adult hospital settings, and who are accessible to the researcher. Thus it is possible that some care experiences may not be reflected in the study narratives.

## **XII. DATA AND SAFETY MONITORING**

- **If the research involves greater than minimal risk and there is no provision made for data and safety monitoring by any sponsor, include a data and safety-monitoring plan that is suitable for the level of risk to be faced by subjects and the nature of the research involved.**
- **If the research involves greater than minimal risk, and there is a provision made for data and safety monitoring by any sponsor, describe the sponsor’s plan.**
- **If you are serving as a Sponsor-Investigator, identify the Contract Research Organization (CRO) that you will be using and describe the provisions made for data and safety monitoring by the CRO. Guidance on additional requirements for Sponsor-Investigators is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#X-2.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#X-2.htm)**



This research involves no more than minimal risk to participants. No adverse consequences are anticipated. The use of numbered filing and pseudonyms throughout the study will ensure confidentiality. There will be no participant names on the study forms and all material associated with the study will be stored in a fire-proof locked file cabinet in the VCU School of Nursing.

### **XIII. MULTI-CENTER STUDIES**

If VCU is the lead site in a multi-center project or the VCU PI is the lead investigator in a multi-center project, describe the plan for management of information that may be relevant to the protection of subjects, such as reporting of unexpected problems, project modifications, and interim results.

NA

### **XIV. INVOLVEMENT OF NON-VCU INSTITUTIONS/SITES (DOMESTIC AND FOREIGN)**

1. Provide the following information for each non-VCU institution/site (domestic and foreign) that has agreed to participate:

- Name of institution/site
- Contact information for institution/site

NA

2. For each institution, indicate whether or not it is “engaged” in the research (see OHRP’s guidance on “Engagement of Institutions in Research” at <http://www.hhs.gov/ohrp/humansubjects/assurance/engage.htm>.)

NA

3. Provide a description of each institution’s role (whether engaged or not) in the human subjects research, adequacy of the facility (in order to ensure human subject safety in the case of an unanticipated emergency), responsibilities of its agents/employees, and oversight that you will be providing in order to ensure adequate and ongoing protection of the human subjects. You should only identify institutions that have agreed to participate. If additional institutions agree to participate at a later time, they must be added by amendment to the protocol.

NA

4. For each institution that is “engaged” provide an OHRP Federalwide Assurance (FWA) # if: (1) the research is not exempt, AND (2) the research involves a DIRECT FEDERAL award made to VCU (or application for such).

**NOTE:** Additional guidance at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-6.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-6.htm), and [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-11.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-11.htm).

NA

## **XV. INVOLVEMENT OF INDEPENDENT INVESTIGATORS**

***INDEPENDENT INVESTIGATOR:*** an individual who is acting independently and not acting as an agent or employee of any institution or facility while carrying out his or her duties in the research protocol. Additional guidance at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-15.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-15.htm).

***ENGAGEMENT IN RESEARCH:*** An independent investigator becomes "engaged" in human subjects research when he/she (i) intervenes or interacts with living individuals for research purposes; or (ii) obtains individually identifiable private information for research purposes [45 CFR 46.102(d)-(f)]. See OHRP's guidance on "Engagement of Institutions in Research" at <http://www.hhs.gov/ohrp/humansubjects/assurance/engage.htm>.

1. Provide a list of independent investigators.
2. For each independent investigator indicate whether or not he/she is "engaged" or "not engaged" in the research
3. For each independent investigator who is "engaged": (1) describe his/her role with human subjects/identifiable human data, AND (2) describe YOUR oversight of his/her involvement.

NA

**NOTE:** If an independent investigator is "engaged," and the research is (1) not exempt AND (2) involves a DIRECT FEDERAL award made to VCU (or application for such), the independent investigator must sign a formal written agreement with VCU certifying terms for the protection of human subjects. For an agreement to be approved: (1) the PI must directly supervise all of the research activities, (2) agreement must follow the ORSP template, (3) IRB must agree to the involvement of the independent investigator, AND (4) agreement must be in effect prior to final IRB approval.

## **XVI. HUMAN SUBJECTS INSTRUCTIONS (Be sure to use the sub-headings under A-I)**

**ALL sections of the Human Subjects Instructions must be completed with the exception of the section entitled "Special Consent Provisions." Complete that section if applicable.**

### **A. DESCRIPTION**

Provide a detailed description of the proposed involvement of human subjects or their private identifiable data in the work.

Up to 15 participants will be recruited for this study. Inclusion criteria for the study will consist of the following: 1) being currently employed as an RN within an adult inpatient



clinical care area, in either an academic or community hospital setting; 2) understand, read and speak English; 3) having completed a comprehensive end-of-life education program or training curriculum, such as ELNEC; and 4) having direct end-of-life patient care experience after completion of the end-of-life training.

After explaining purpose of the study to potential participants and answering initial questions, the researcher will ask participants to state whether they meet inclusion criteria. *(See recruitment narrative attached to this document)*. After completion of the informed consent process and as participants are enrolled in the study, demographic data will be obtained; demographic data from all participants will be aggregated and summarized on an ongoing basis. Individual and aggregated demographic data will contribute to a description of the study sample in written research reports. *(The demographic data form is attached to this document)*.

Interviews will be conducted separately with each participant. Interviews are expected to last up to 60 minutes and will be audio-recorded. All interviews will be conducted in a private, quiet area at a setting that is selected by or convenient to the participant. *(A copy of interview questions is attached to this document)*.

## **B. SUBJECT POPULATION**

**Describe the subject population in terms of sex, race, ethnicity, age, etc., and your access to the population that will allow recruitment of the necessary number of participants. Identify the criteria for inclusion or exclusion of any subpopulation and include a justification for any exclusion. Explain the rationale for the involvement of special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable. If you plan to allow for the enrollment of Wards of the State (or any other agency, institution, or entity), you must specifically request their inclusion and follow guidance on Wards and Emancipated Minors in the VCU IRB Written Policies and Procedures (specifically WPP#: XV-3) available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XV-3.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XV-3.htm).**

The subject population is professional nurses who are currently employed and have completed an end-of-life training program, and at some point after end-of-life care education, have provided care to adult patients in an inpatient setting. The inclusion criteria were established to ensure that study participants have had experiences relevant to the study focus. In order to develop an understanding of a phenomenon from qualitative data, it is necessary to study a sample of individuals who have experienced that particular phenomenon.

The sample will likely reflect the demographics of the nursing profession: white, female and middle-aged. The sample will understand, read and speak English. As a result of the educational requirements to become a professional nurse, all participants will be at least 18 years old. No children, fetuses, neonates, prisoners or others who are likely to be vulnerable will be included as they would not meet inclusion criteria. Nurses who are able to maintain currently professional employment while pregnant would be eligible, as participation in the study would not constitute a risk to the pregnancy. Pregnant nurses are NOT the focus of recruitment efforts, however.

Access to the population of interest will be facilitated by a wide distribution of the study recruitment information flyer. Distribution of the flyer at VCUHS alone will ensure that over 500 nurses who work in adult units will learn about the opportunity to participate in the study. Distribution of the recruitment information flyer to professional contacts and members of

professional organizations in the Richmond area will ensure that nurses working in other settings will also become aware of the opportunity to participate in this study.

### C. RESEARCH MATERIAL

**Identify the sources of research material obtained from individually identifiable living human subjects in the form of specimens, records, or data. Indicate whether the material or data will be obtained specifically for research purposes or whether use will be made of existing specimens, records, or data.**

Research material will consist of recruitment narrative, recorded participant interview sessions, electronic and paper versions of interview transcripts, researcher field notes, researcher reflection journal, and participant demographic data. All material associated with and derived from this study will be for the sole purpose of research. All data will be de-identified. No data will be stored directly on the computer; a portable disk will be used for maintaining electronic data. A back-up disk will also be used to facilitate protection of stored data. The digital audio-recorder and disks containing electronic transcribed interview text, as well as all other research data will be safeguarded in a locked fire-proof container stored in the VCU School of Nursing. All data generated from this study will be destroyed within 12 months following completion of the study in accord with the policies and guidelines of Virginia Commonwealth University Office of Research.

### D. RECRUITMENT PLAN

**Describe in detail your plans for the recruitment of subjects including: (1) how potential subjects will be identified (e.g., school personnel, health care professionals, etc), (2) how you will get the names and contact information for potential subjects, and (3) who will make initial contact with these individuals (if relevant) and how that contact will be done. If you plan to involve special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable, describe any special recruitment procedures for these populations.**

Recruitment of potential participants will be accomplished through posting of an information flyer about the study in nurse-accessible locations within VCU Health System’s inpatient areas, as well as distribution of information about the study to professional contacts, community-based coordinators for ELNEC training, and other community-based nurse leaders with professional interest in end-of-life care who are willing to share the recruitment information flyer with nurses employed in adult inpatient clinical care settings. ***(A copy of the recruitment information flyer is attached to this document)***. Additionally, the researcher will personally distribute the information flyer about the study to leaders of local chapters of professional organizations, such as the Richmond chapter of the Oncology Nursing Society and the Richmond area chapter of American Association of Critical Care Nurses. The names and contact information for community nurse leaders will be obtained from VCU School of Nursing professors or by personal professional networking. Distribution of information about the study will be initiated after obtaining formal permission to distribute that information within an organization or facility.

The recruitment information flyer about the study will include instructions asking those

who are interested in participating in the study or who may have questions about the study to contact the researcher directly, by phone, email, or in person. When nurses interested in participating in the study contact the researcher, she will explain the purpose of the study and assess whether the interested nurse meets inclusion criteria. *Inclusion criteria include the following:* 1) being currently employed as an RN within an adult inpatient clinical care area, in either an academic or community hospital setting; 2) understand, read and speak English; 3) having completed a comprehensive end-of-life education program or training curriculum, such as ELNEC; and 4) having direct patient care experience after completion of the end-of-life training.

If it is determined by the researcher that a prospective participant does not meet study inclusion criteria, the individual will be informed of this and thanked for his or her interest in the study. If it is determined that the potential participant meets inclusion criteria for the study, he/she will be informed that the study involves an interview that will be audio-taped and may take up to 60 minutes depending upon what he/she would like to share regarding experiences in providing end-of-life care. The participant will also be informed that responses will not be personally identified with him/her. If the potential participant expresses interest in the study, he/she will be asked if a packet of information that includes details about the study and a consent form can be forwarded to him/her by email, postal mail or personal delivery. If the participant agrees to receive the materials, the researcher will send the materials and then follow up within a week via the participant preferred method of communication. The participant will also be provided the option to initiate the follow up. At the time of the follow up contact, if the potential participant agrees to participate in the study he/she will be asked to schedule date, time and location for completing the informed consent document and conducting the interview session. *(The recruitment narrative and the Research Subject Information Consent form are attached to this document).*

#### **E. POTENTIAL RISKS**

**Describe potential risks whether physical, psychological, social, legal, or other and assess their likelihood and seriousness. Where appropriate, describe alternative treatments and procedures that might be advantageous to the subjects.**

This research presents no more than minimal risk to its participants. It is possible that some nurses may experience temporary emotional distress during the interview as they discuss their experiences caring for dying or deceased patients or their families.

#### **F. RISK REDUCTION**

**Describe the procedures for protecting against or minimizing potential risk. Where appropriate, discuss provisions for ensuring necessary medical or professional intervention in the event of adverse events to the subjects. Also, where appropriate, describe the provisions for monitoring the data collected to ensure the safety of subjects.**

The risks associated with this study are minimal. However, in order to facilitate participant comfort with the interview process, the following steps will be taken: participants will be given the opportunity to select the location of the interview; informed consent will be obtained and permission will be sought for use of audio recording during the interview; participants will

be informed and reminded that they can stop the interview and/or withdraw from the study at any time. Additionally, since end-of-life care experiences may be associated with distress, personal discomfort, or negative emotions, the researcher will be observant of the emotional state of each participant. The researcher is a highly qualified nurse experienced in dealing with individuals dealing with distress. If the participant demonstrates signs of personal or emotional distress or discomfort, the interview will be temporarily stopped and the participant will be provided options by the researcher to continue the interview, reschedule the interview, or withdraw from the study. Participants who demonstrate distress will be encouraged to seek support from a counselor, minister, or other appropriate person and he or she will be informed that this support will not result in cost to the project.

#### **G. ADDITIONAL SAFEGUARDS IF ANY PARTICIPANTS WILL BE VULNERABLE**

**Describe any additional safeguards to protect the rights and welfare of participants if you plan to involve special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable. Safeguards to protect the rights and welfare of participants might relate to Inclusion/Exclusion Criteria: (“Adults with moderate to severe cognitive impairment will be excluded.” “Children must have diabetes. No normal controls who are children will be used.”) Consent: (“Participants must have an adult care giver who agrees to the participant taking part in the research and will make sure the participant complies with research procedures.” “Adults must be able to assent. Any dissent by the participant will end the research procedures.”) Benefit: (“Individuals who have not shown benefit to this type of drug in the past will be excluded.”).**

NA

#### **H. CONFIDENTIALITY**

**Describe how the confidentiality of data collected as part of this project will be protected including pre-screening data (e.g., physical controls on the data; access controls to the data; coding of data; legal controls, such as a Federal Certificate of Confidentiality; statistical methods; or reporting methods).**

The log of participant names and contact information will be maintained in a locked cabinet in the VCU School of Nursing in a location separate from the data. Transcripts of all interview sessions will be numbered and dated. Participants will be assigned an interview number and related data will be de-identified. No medical record or patient-specific data will be gathered. Electronic copies of transcript data will be stored on a separate portable storage device/disk. Additionally, if the interviews are professionally transcribed, the transcriptionist will have completed human subjects training and will be required to sign a confidentiality statement. The digital audio-recorder containing tape-recorded participant interviews, electronic transcript data, and all textual data for this study will be stored in the VCU School of Nursing in a locked fire-proof file cabinet. De-identified data will be available to researchers and to appropriate regulatory agencies as required. Findings will be reported by the use of assigned pseudonyms.

## **I. PRIVACY**

**Describe how the privacy interests of subjects will be protected where privacy refers to persons and their interests in controlling access to themselves, and assess their likely effectiveness. Identify what steps you will take for subjects to be comfortable: (1) in the research setting and (2) with the information being sought and the way it is sought.**

In order to facilitate participant privacy and comfort with the interview process, the following steps will be taken: participants will be given the opportunity to select the location of the interview; informed consent will be obtained and permission will be sought for use of audio recording during the interview; all data will be de-identified. Interviews will be conducted separately with each participant in a quiet, private area within the setting chosen by or convenient to the participant. Permission will be obtained from each participant to contact him/her again if there is a need for clarification of any information obtained in the interview session. Research findings will be reported by the use of assigned pseudonyms.

## **J. RISK/BENEFIT**

**Discuss why the risks to subjects are reasonable in relation to the anticipated benefits to subjects and in relation to the importance of the knowledge that may reasonably be expected to result. If a test article (investigational new drug, device, or biologic) is involved, name the test article and supply the FDA approval letter.**

The minimal risk to participants is reasonable in relation to the benefit of increased knowledge.

## **K. COMPENSATION PLAN**

**Compensation for subjects (if applicable) should be described, including possible total compensation, any proposed bonus, and any proposed reductions or penalties for not completing the project.**

Subjects will not be compensated for participating in the study and there will be no penalties for not participating.

## **L. CONSENT ISSUES**

### **1. CONSENT PROCESS**

**Indicate who will be asked to provide consent/assent, who will obtain consent/assent, what language (e.g., English, Spanish) will be used by those obtaining consent/assent, where and when will consent/assent be obtained, what steps will be taken to minimize the possibility of coercion or undue influence, and how much time will subjects be afforded to make a decision to participate.**

The recruitment information flyer about the study will include instructions asking those who are interested in participating in the study or who may have questions about the study to contact the researcher directly, by phone, email, or in person. When nurses interested in participating in the study contact the researcher, she will explain the purpose of the study and assess whether the interested nurse meets inclusion criteria.

If it is determined by the researcher that a prospective participant does not meet study inclusion criteria, the individual will be informed of this and thanked for his or her interest in the study. If it is determined that the potential participant meets inclusion criteria for the study, he/she will be informed that the study involves an interview that will be audio-taped and may take up to 60 minutes depending upon what he/she would like to share regarding experiences in providing end-of-life care. The participant will also be informed that responses will not be personally identified with him/her. If the potential participant expresses interest in the study, he/she will be asked if a packet of information that includes details about the study and a consent form can be forwarded to him/her by email, postal mail or personal delivery. If the participant agrees to receive the materials, the researcher will send the materials and then follow up within a week via the participant preferred method of communication. The participant will also be provided the option to initiate the follow up. At the time of the follow up contact, if the potential participant agrees to participate in the study he/she will be asked to schedule date, time and location for completing the informed consent document and conducting the interview session. ***(The recruitment narrative and the Research Subject Information Consent form are attached to this document).***

1. Consent Setting - The informed consent process will be completed by the researcher at a location and setting that is selected by or convenient to the participant. The participants' consent to participate is implied by their completion and returning of the forms. Contact information for the researcher, Principal Investigator (PI) and the Office of Research Subjects Protection is provided so that any questions may be answered.
2. Comprehension - Participants will be registered nurses, and thus should be able to understand the materials, as well as their involvement and rights concerning the study. The researchers will be available to answer any questions related to the study. All written materials will be in the English language and participants will understand, read and speak English.

## 2. SPECIAL CONSENT PROVISIONS

If some or all subjects will be cognitively impaired, or have language/hearing difficulties, describe how capacity for consent will be determined. Please consider using the VCU Informed Consent Evaluation Instrument available at <http://www.research.vcu.edu/irb/guidance.htm>. If you anticipate the need to obtain informed consent from legally authorized representatives (LARs), please describe how you will identify an appropriate representative and ensure that their consent is obtained. Guidance on LAR is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XI-3.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XI-3.htm).

NA

3. If request is being made to **WAIVE SOME OR ALL ELEMENTS OF INFORMED CONSENT FROM SUBJECTS OR PERMISSION FROM PARENTS**, explain why: (1) the research involves no more than minimal risk to the subjects, (2) the waiver or alteration will not adversely affect the rights and welfare of the subjects, (3) the research could not practicably be carried out without the waiver or alteration; AND (4) whether or not subjects will be debriefed after their participation. Guidance is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XI-1.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XI-1.htm). **NOTE:** Waiver is not allowed for FDA-regulated research unless it meets FDA requirements for Waiver of Consent for Emergency Research (see below).

NA

4. If request is being made to **WAIVE DOCUMENTATION OF CONSENT**, provide a justification for



waiver based on one of the following two elements AND include a description of the information that will be provided to participants: (1) the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Subject will be asked whether they want documentation linking them with the research, and each subject’s wishes will govern; or (2) the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context. Guidance is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XI-2.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XI-2.htm)

NA

5. If applicable, explain the **ASSENT PROCESS** for children or decisionally impaired subjects. Describe the procedures, if any, for re-consenting children upon attainment of adulthood. Describe procedures, if any, for consenting subjects who are no longer decisionally impaired. Guidance is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XV-2.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XV-2.htm).and [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-7.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-7.htm).

NA

6. If request is being made to **WAIVE THE REQUIREMENT TO OBTAIN ASSENT** from children age 7 or higher, or decisionally impaired subjects, explain why: (1) why some or all of the individuals age 7 or higher will not be capable of providing assent based on their developmental status or impact of illness; (2) the research holds out a prospect of direct benefit not available outside of the research; AND/OR (3) [a] the research involves no more than minimal risk to the subjects, [b] the waiver or alteration will not adversely affect the rights and welfare of the subjects, [c] the research could not practicably be carried out without the waiver or alteration; AND [d] whether or not subjects will be debriefed after their participation. Guidance is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XV-2.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XV-2.htm)

NA

7. If request is being made to waive consent for emergency research, see guidance at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-16.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-16.htm).

NA

8. If applicable, address the following issues related to **GENETIC TESTING**:

**a. FUTURE CONTACT CONCERNING FURTHER GENETIC TESTING RESEARCH**

Describe the circumstances under which the subject might be contacted in the future concerning further participation in this or related genetic testing research.

NA

**b. FUTURE CONTACT CONCERNING GENETIC TESTING RESULTS**

If planned or possible future genetic testing results are unlikely to have clinical implications, then a statement that the results will not be made available to subjects may be appropriate. If results might be of clinical significance, then describe the circumstances and procedures by which subjects would receive results. Describe how subjects might access genetic counseling for assistance in understanding the implications of genetic testing results, and whether this might involve costs to subjects. Investigators should be aware that federal regulations, in general, require that testing

results used in clinical management must have been obtained in a CLIA-certified laboratory.

NA

**c. WITHDRAWAL OF GENETIC TESTING CONSENT**

Describe whether and how subjects might, in the future, request to have test results and/or samples withdrawn in order to prevent further analysis, reporting, and/or testing.

NA

**d. GENETIC TESTING INVOLVING CHILDREN OR DECISIONALLY IMPAIRED SUBJECTS**

Describe procedures, if any, for consenting children upon the attainment of adulthood. Describe procedures, if any, for consenting subjects who are no longer decisionally impaired.

NA

**e. CONFIDENTIALITY**

Describe the extent to which genetic testing results will remain confidential and special precautions, if any, to protect confidentiality.

NA

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## Appendix B

### “Understanding Nurses’ Experiences of Providing End-of-Life Care in the United States Hospital Setting”

#### Recruitment Script

Thank you for contacting me about the research study, “Understanding Nurses’ Experiences of Providing End-of-Life Care” that is being conducted by researchers from Virginia Commonwealth University (VCU). The purpose of the study is to develop an understanding of nurses’ experiences of providing end-of life care. It will take about 5 minutes of your time to hear more about this study. Is it OK for me to continue?

If you qualify to be included, there will be no payment for your participation in the study. Your decision about whether to be in the study or not will not affect your current employment in any way. The study is totally separate from your employment.

Here are the criteria to be in this study:

- currently working for pay as an RN in a hospital in an adult care setting,
- understand, read and speak English,
- having completed a comprehensive end-of-life education program or training curriculum, such as ELNEC;
- having direct patient care experience since you completed the end-of-life training.

Do you meet these criteria and are you interested in knowing more about the study?

If NO: Thank you for your call. If you know others who may qualify and who may be interested, I would be grateful if you could tell them about this study. Thank you for your call.

If YES: The study involves an interview that will be audio-taped and may take up to 60 minutes depending on what you would like to share with me regarding your experiences in providing end-of-life care. What you share with me will not be personally identified with you.

Would you be willing for me to mail to you a packet of information about the study that includes more detail and a consent form that you will be asked to sign? If you agree to receive the materials, I will contact you or ask you to contact me within a week to answer any questions. Then, if you decide to participate you will be asked to complete the informed consent process and schedule an interview.

If YES: To what address or email should I send the materials? Do you prefer to contact me or may I have your contact email or telephone number to answer any questions and schedule the interview if you decide to participate?

## Appendix C

### “Understanding Nurses’ Experiences of Providing End-of-Life Care in the United States Hospital Setting”

#### Interview Questions

##### Investigators:

D. Patricia Gray, PhD, RN – Principal Investigator (responsible for research and will serve as primary contact)

Susan C. Johnson, RN, MS – Student Researcher

##### Interview Questions:

Semi-structured face-to-face interviews will be conducted by the researcher. Participants will be asked to share thoughts, feelings, reflections and experiences in providing end-of-life care for patients or their families. Additional questions may be posed in order to explore context and meaning of reflections, experiences, or comments that are verbalized. Each interview is expected to last up to 60 minutes, depending on details of the responses and will be audio-recorded. Interviews will be conducted separately with each participant in a private, quiet area at a setting that is convenient to the participant.

Interview questions are as follows:

- Please share information regarding your nursing background and your original and ongoing interests in end of life nursing care.
- Please tell me about end-of-life care experiences that are particularly meaningful or stand out for you.
- Do you have any additional thoughts, reflections or information regarding this subject that you would like to share with me?

## Appendix D

### “Understanding Nurses’ Experiences of Providing End-of-Life Care in the United States Hospital Setting”

#### Demographic Data Collection Form

**Investigators:**

D. Patricia Gray, PhD, RN – Principal Investigator (responsible for research and will serve as primary contact)

Susan C. Johnson, RN, MS – Student Researcher

**Age:** \_\_\_\_\_

**Gender:**

Male \_\_\_\_\_

Female \_\_\_\_\_

**Ethnicity:**

African-American \_\_\_\_\_

Non- Hispanic White \_\_\_\_\_

Hispanic \_\_\_\_\_

Pacific Island-Asian \_\_\_\_\_

Other \_\_\_\_\_

**Highest Level of Nursing Education:**

Associate Degree \_\_\_\_\_

Diploma \_\_\_\_\_

Baccalaureate Degree \_\_\_\_\_

Masters Degree \_\_\_\_\_

Other \_\_\_\_\_

**Employment:**

Academic Medical Center \_\_\_\_\_

Community Hospital \_\_\_\_\_

**Clinical Work Setting:**

Palliative Care \_\_\_\_\_

Oncology \_\_\_\_\_

Medical-Surgical \_\_\_\_\_

Critical Care \_\_\_\_\_

Progressive Care \_\_\_\_\_

Other \_\_\_\_\_

**End-of-Life Care Training: Date of Completion** \_\_\_\_\_

**Name of Training Program** \_\_\_\_\_

**Years of Clinical Experience since End-of-Life Care Training:** \_\_\_\_\_

## Appendix E

### “Understanding Nurses’ Experiences of Providing End-of-Life Care in the United States Hospital Setting”

# VCU Memo

Virginia Commonwealth University

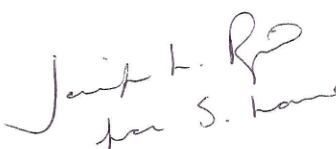
Office of Research Subjects Protection  
BioTechnology Research Park  
BioTech One, 800 E. Leigh Street, #114  
P.O. Box 980568  
Richmond, Virginia 23298-0568  
(804) 828-3992  
(804) 827-1448 (fax)

DATE: June 25, 2009

TO: D. Patricia Gray, PhD, RN  
School of Nursing  
Box 980567

FROM: Shelly J. Lane, PhD  
Vice Chairperson, VCU IRB Panel B  
Box 980568

RE: **VCU IRB #: HM12314**  
**Title: Understanding Nurses’ Experiences of Providing End-of-Life Care**



On June 25, 2009, the following research study was **approved** by expedited review according to 45 CFR 46.110 Category 6. This approval includes the following items reviewed by this Panel:

**RESEARCH APPLICATION/PROPOSAL:** None

**PROTOCOL (Research Plan):** Understanding Nurses’ Experiences of Providing End-of-Life Care, received 6/16/09, version 1, dated 6/8/09

- Demographic Data Collection Form, received 6/16/09, version 1, dated 6/8/09
- Interview Questions, received 6/16/09, version 1, dated 6/8/09

**CONSENT/ASSENT (attached):**

- Research Subject Information and Consent Form, received 6/16/09, version 1, dated 6/8/09, 4 pages

**ADDITIONAL DOCUMENTS (attached):**

- Participant Information Cover Letter, received 6/16/09, version 1, dated 6/8/09
- Recruitment Script, received 6/16/09, version 1, dated 6/8/09
- Flyer: Nurse Participants Needed, received 6/16/09, version 1, dated 6/8/09

**This approval expires on May 31, 2010.** Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

The Primary Reviewer assigned to your research study is Lou Usry, RN. If you have any questions, please contact Ms. Usry at [lusry@mcvh-vcu.edu](mailto:lusry@mcvh-vcu.edu) and 828-9229; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at [jlrice@vcu.edu](mailto:jlrice@vcu.edu) and 828-3992.

[Attachment – Conditions of Approval]

Page 1 of 2



**Conditions of Approval:**

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must (*as applicable*):

1. Conduct the research as described in and required by the Protocol.
2. Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved or research is exempt).
3. Document informed consent using only the most recently dated consent form bearing the VCU IRB “APPROVED” stamp (unless Waiver of Consent is specifically approved).
4. Provide non-English speaking patients with a translation of the approved Consent Form in the research participant's first language. The Panel must approve the translated version.
5. Obtain prior approval from VCU IRB before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research participants (e.g., permanent/temporary change of PI, addition of performance/collaborative sites, request to include newly incarcerated participants or participants that are wards of the state, addition/deletion of participant groups, etc.). Any departure from these approved documents must be reported to the VCU IRB immediately as an Unanticipated Problem (see #7).
6. Monitor all problems (anticipated and unanticipated) associated with risk to research participants or others.
7. Report Unanticipated Problems (UPs), including protocol deviations, following the VCU IRB requirements and timelines detailed in VCU IRB WPP VIII-7:
8. Obtain prior approval from the VCU IRB before use of any advertisement or other material for recruitment of research participants.
9. Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.
10. All protocols that administer acute medical treatment to human research participants must have an emergency preparedness plan. Please refer to VCU guidance on <http://www.research.vcu.edu/irb/guidance.htm>.
11. The VCU IRBs operate under the regulatory authorities as described within:
  - a) U.S. Department of Health and Human Services Title 45 CFR 46, Subparts A, B, C, and D (for all research, regardless of source of funding) and related guidance documents.
  - b) U.S. Food and Drug Administration Chapter I of Title 21 CFR 50 and 56 (for FDA regulated research only) and related guidance documents.
  - c) Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research).

[010507]

“Understanding Nurses’ Experiences of Providing End-of-Life Care”  
Research Subject Information and Consent Form: Attachment #4  
Gray/Johnson IRB – Version 1 (6-08-09)



## RESEARCH SUBJECT INFORMATION AND CONSENT FORM

### TITLE: “Understanding Nurses’ Experiences of Providing End-of-Life Care”

This consent form may contain words or information that you do not understand. Please ask the investigator to explain any words or information that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family, friends, or colleagues before making your decision.

### PURPOSE OF THE STUDY

The goal of this research study is to develop an understanding of registered nurses’ experiences of providing end-of-life care for adult inpatients. You are being asked to participate in this study because you have identified yourself as a registered nurse who is employed to care for adult patients in the hospital setting and as someone who has completed comprehensive end-of-life nursing education or an end-of-life training program, such as the End of Life Nursing Education Consortium (ELNEC) program.

### DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to participate in this research study, you will be asked to sign this consent form after you have had all of your questions answered, and you understand what will happen to you.

In this study, you will be asked to meet with a member of the research team, Susan Johnson, for about 60 minutes. During that time, she will first ask you some questions about yourself and your work history (work setting, time that has elapsed since completion of end-of-life training or curriculum completion). Then she will ask you to describe your experiences with end of life care. Specifically, she will ask you:

- To describe your nursing background and your original and ongoing interest in end of life nursing care.
- To share your end-of-life nursing care experiences.
- To share any additional thoughts, reflections or information regarding this subject.

Interviews will be conducted in a private area at a setting that is convenient to you. The interviews will be tape recorded; however, no names will be used or recorded on the tape. During or after the interview, Ms. Johnson may contact you or ask you additional questions to help her clarify or understand information as it relates to your experiences. Your total time involvement will be approximately 60 minutes.

### RISKS AND DISCOMFORTS

Sometimes talking about dying or deceased patients or experiences in providing care for dying patients or their families causes some nurses to become emotionally upset. You do not have to talk about any subject you do not want to talk about, and you may stop the interview at any time. If you become upset and the study staff assesses that you may benefit from support, she will encourage you to seek support from a counselor, minister, or other appropriate person.

1

APPROVED

6-25-09/LU / JJR

“Understanding Nurses’ Experiences of Providing End-of-Life Care”  
Research Subject Information and Consent Form: Attachment #4  
Gray/Johnson IRB – Version 1 (6-08-09)

### **BENEFITS TO YOU AND OTHERS**

You may not receive direct benefit from this study, but what we learn from the participants in this study will help us to gain an understanding of important information regarding end-of-life nursing care.

### **COSTS**

There are no costs for participating in this study other than the time you will spend in the interview or on a follow up call or meeting, if this is necessary.

### **CONFIDENTIALITY**

Potentially identifiable information about you will consist of demographic information, interview notes, audiotapes of interviews, and transcriptions of audiotapes. Data are being collected only for research purposes. Personal identifying information will include your name and contact information which will be stored in a separate location from your demographic and interview data. Your data will not include your personal identifying information. It will be identified by an ID number, not name, and it will be stored in a locked file cabinet. Audiotapes, data, and personal identifying information will be kept in a locked file cabinet for twelve months after the study ends and they will be destroyed at that time.

We will not tell anyone about the personal information you provide to us, however, de-identified information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University.

What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

### **IF AN INJURY HAPPENS**

Virginia Commonwealth University and the VCU Health System (also known as MCV) do not have a plan to provide care or money if you are injured because you are in this study. If you are injured because of being in this study, tell the study staff right away and they will arrange for short-term emergency care or referral if it is needed. Bills for treatment may be sent to you or your insurance. Your insurance may or may not pay for taking care of injuries that happen because of being in this study.

### **VOLUNTARY PARTICIPATION AND WITHDRAWAL**

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

Your participation in this study may be stopped at any time by the study staff without your consent. The reasons might include:

- The study staff thinks it is necessary for your health or safety; or
- Administrative reasons require your withdrawal.

2

**APPROVED**

6-25-09 / LU / JRC

“Understanding Nurses’ Experiences of Providing End-of-Life Care”  
Research Subject Information and Consent Form: Attachment #4  
Gray/Johnson IRB – Version 1 (6-08-09)

### QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

D. Patricia Gray, PhD, RN, Associate Professor of Nursing  
School of Nursing  
Virginia Commonwealth University  
1100 E. Leigh Street  
Richmond, Virginia 23298  
(804) 828-3320

Mailing Address:  
PO Box 980567  
Richmond, VA 23298-0567

Or you may contact:  
Susan C. Johnson, RN, MS  
14008 Canterbury Road  
Montpelier, VA 23192  
(804) 883-7571 (H)  
(804) 938-0496 (C)

If you have any questions regarding your rights as a participant in this study, you may contact:  
Office for Research  
Virginia Commonwealth University  
800 East Leigh Street, Suite 113  
PO Box 980568  
Richmond, VA 23298  
(804) 827-2157

You may also contact the Office of Research for general questions, concerns about your rights, questions about injury, or complaints about the research. Please call the Office of Research if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

3

APPROVED

6-25-09 / LU / JR

“Understanding Nurses’ Experiences of Providing End-of-Life Care”  
Research Subject Information and Consent Form: Attachment #4  
Gray/Johnson IRB – Version 1 (6-08-09)

**CONSENT**

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

\_\_\_\_\_  
Participant Name Printed

\_\_\_\_\_  
Participant Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Person Conducting Informed Consent Discussion/Witness  
Printed

\_\_\_\_\_  
Signature of Person Conducting Informed Consent Discussion/Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Investigator Signature (if different from above)

\_\_\_\_\_  
Date

4

**APPROVED**

6-25-09 / LU / JTR



“Understanding Nurses’ Experiences of Providing End-of-Life Care”  
Participant Information Cover Letter: Attachment #3  
Gray/Johnson IRB – Version 1 (6-08-09)

14008 Canterbury Road  
Montpelier, VA 23192  
Date



Dear \_\_\_\_\_,

Thank you for your interest in the study “Understanding Nurses’ Experiences of Providing End-of-Life Care.” I have enclosed a packet of information for your review that addresses the following: description of the study, participant information, interview questions and informed consent. Kindly review the enclosed information materials and if you have questions regarding this study, you may contact me at any time. Additionally you may contact the principal investigator, or Virginia Commonwealth University Office of Research Subjects Protection. Contact information is included with this letter.

I will contact you within a week (or: kindly contact me within a week) as per our discussion. At that time, if you are interested in study participation I will schedule a date, time, and place convenient to you to complete the informed consent and conduct the interview.

Thank you.

Sincerely,

Susan C. Johnson, RN, MS

14008 Canterbury Road  
Montpelier, VA 23192  
(804) 883-7571 (H)  
(804) 938-0496 (C)

Or you may contact:

D. Patricia Gray, PhD, RN, Associate Professor  
School of Nursing  
Virginia Commonwealth University  
1100 E. Leigh Street  
Richmond, Virginia 23298  
(804) 828-3320

Mailing Address:  
PO Box 980567  
Richmond, VA 23298-0567

APPROVED

6-25-09 / Lu / JR

“Understanding Nurses’ Experiences of Providing End-of-Life Care”  
Participant Information Cover Letter: Attachment #3  
Gray/Johnson IRB – Version 1 (6-08-09)

If you have any questions regarding your rights as a participant in this study, you may contact:  
Office for Research  
Virginia Commonwealth University  
800 East Leigh Street, Suite 113  
PO Box 980568  
Richmond, VA 23298  
(804) 827-2157

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6-25-09 / Lu / JTR

“Understanding Nurses’ Experiences of Providing End-of-Life Care”  
Recruitment Script: Attachment #2  
Gray/Johnson IRB – Version 1 (6-08-09)

**“Understanding Nurses’ Experiences of Providing End-of-Life Care”**

**Recruitment Script**



Thank you for contacting me about the research study, “Understanding Nurses’ Experiences of Providing End-of-Life Care” that is being conducted by researchers from Virginia Commonwealth University (VCU). The purpose of the study is to develop an understanding of nurses’ experiences of providing end-of life care. It will take about 5 minutes of your time to hear more about this study. Is it OK for me to continue?

If you qualify to be included, there will be no payment for your participation in the study. Your decision about whether to be in the study or not will not affect your current employment in any way. The study is totally separate from your employment.

Here are the criteria to be in this study:

- currently working for pay as an RN in a hospital in an adult care setting,
- understand, read and speak English,
- having completed a comprehensive end-of-life education program or training curriculum, such as ELNEC;
- having direct patient care experience since you completed the end-of-life training.

Do you meet these criteria and are you interested in knowing more about the study?

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If NO: Thank you for your call. If you know others who may qualify and who may be interested, I would be grateful if you could tell them about this study. Thank you for your call.

If YES: The study involves an interview that will be audio-taped and may take up to 60 minutes depending on what you would like to share with me regarding your experiences in providing end-of-life care. What you share with me will not be personally identified with you.

Would you be willing for me to mail to you a packet of information about the study that includes more detail and a consent form that you will be asked to sign? If you agree to receive the materials, I will contact you or ask you to contact me within a week to answer any questions. Then, if you decide to participate you will be asked to complete the informed consent process and schedule an interview.

If YES: To what address or email should I send the materials? Do you prefer to contact me or may I have your contact email or telephone number to answer any questions and schedule the interview if you decide to participate?

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“Understanding Nurses’ Experiences of Providing End-of-Life Care”  
Recruitment Information Flyer: Attachment #1  
Gray/Johnson IRB – Version 1 (6-08-09)



## Nurse Participants Needed

I am a doctoral student in the School of Nursing at Virginia Commonwealth University. I am interested in understanding hospital nurses’ experiences of providing end-of-life care for adult inpatients.



### Please contact me if you:

- are currently employed as an RN in an inpatient adult care setting,
- can understand, read and speak English,
- have completed ELNEC or another end-of-life care training program, and
- are willing to share your thoughts and experiences.

You will be asked to complete a face-to-face interview about your views and experiences of providing end-of-life care to adult patients. Interviews are expected to last up to 60 minutes. Interviews will occur at a time and place that is convenient to you. There is no financial compensation for your participation.

Please call me if you would like to participate or if you have any questions about the study. Participant recruitment is occurring during summer and fall, 2009.

**Susan Johnson, RN, MS**  
Doctoral Student  
VCU School of Nursing  
Home: (804) 883-7571  
Cell: (804) 938-0496  
Email: johnsonsc4@vcu.edu



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6-25-09 / Lu / JJC

## Vita

Susan Carey Williams Johnson was born on January 25, 1950, in Richmond, Virginia, and is a citizen of the United States of America. She graduated from Norfolk Catholic High School, Norfolk, Virginia in 1968. She received a diploma in nursing from DePaul Hospital, Norfolk, Virginia in 1971. She received her Bachelor of Science in Nursing from Virginia Commonwealth University, Richmond, Virginia in 1973. After an honorable discharge from the United States Navy Nurse Corps she received her Master of Science from Virginia Commonwealth University, Richmond, Virginia in 1981. She subsequently worked in community hospital settings in central Virginia for over 25 years. Her professional positions have included staff nurse, nursing educator, Nurse Manager, Director of Nursing, Director of Quality Management, Associate Administrator, and Chief Nursing Officer. She received a Doctor of Philosophy in Nursing from Virginia Commonwealth University, Richmond, Virginia in 2010.