THE EXPERIENCE OF CARING FOR THE HOSPITALIZED PATIENT AT END OF LIFE

By

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To all of the healthcare providers who are present with a patient at end of life
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THE EXPERIENCE OF CARING FOR THE HOSPITALIZED PATIENT AT END OF LIFE

By

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This study explored the experiences and perceptions of ten healthcare providers (physicians, nurses and nursing assistants) who cared for six dying patients in general medical-surgical units of an acute care hospital. Audio taped in-depth interviews in which the participants told their personal stories were transcribed verbatim and analyzed using Riessman’s method of narrative analysis.

The narratives provided substantial evidence that the death of a patient is a significant and meaningful event and suggested that after the death, providers may have feelings of sadness and empathy for the patients and families and sometimes relief that the suffering is over. The participants were interested in facilitating a “good death” for their patients by working toward and/or maintaining a sense of harmony among the patients, families and healthcare providers. If there was indecision or nonacceptance of the careplan, the provider felt uncomfortable and disharmony.

Some of the key factors that were identified by the analysis of the narratives which affected the providers’ abilities to facilitate a good death and promote harmony are (1) experience and knowledge of the provider, (2) openness of dialogue among providers, patients,
and families (3) attention to comfort of the patient, (4) providing support to the family (5) consensus in the plan of care among providers and family and (6) the patient not dying alone.

The providers were also cognizant of other providers’ roles in caring for patients at the end of life. Disharmony and conflict can ensue if one provider does not perceive the other is providing quality care. The providers felt a sense of harmony when they felt supported by others, respected and valued as a team member and the event of a patient’s death is positive and meaningful.

The harmony/disharmony in these narratives illustrates the implications of many barriers in how the healthcare providers perceive the experiences. When harmony is achieved among the patient, family and staff, the experience for the healthcare provider is viewed as meaningful and positive. Disharmony increases the stress and emotional burden of the healthcare provider and can have repercussions on the quality of care the patient receives.
CHAPTER 1
THE PROBLEM

Introduction

I have observed in my roles of nurse and educator, the suffering of patients, families and the staff when caring for dying patients in the acute care hospital. Often, my coworkers would recount their experiences by telling stories of caring for the dying patient and family to each other. There seemed to be a need to share their experiences. Why do we have the need to tell these stories? Frankl (1984) stated that man is motivated to find meaning from suffering. Does telling a story help the healthcare provider find meaning from suffering? This dissertation examines the experiences of healthcare providers who have cared for a patient at end of life through narrative analysis of their stories.

The current end of life research centers primarily on the patient and the family; there exists little research on professional caregivers’ experiences in the general medical-surgical unit. The few studies of professional caregivers at end of life have focused on nurses and physicians in the Intensive Care Unit (ICU) or hospice/palliative care environments (Wennber et al., 2004). Healthcare practice and the roles of the healthcare provider have changed dramatically in the past 50 years due to increased knowledge in biomedical science and the application of technology. Today’s hospitalized patient is more acutely ill and receives highly technical care in all areas of the hospital, not just the ICU. The general medical-surgical healthcare provider must be competent to provide highly technical skills that were once reserved for only intensive care units as part of the daily care of the patient. More research is needed to understand the effect of the death of a patient on the healthcare provider in the non-ICU setting.

The aim of this dissertation is to explore the perceptions of nurses, physicians and nursing assistants as they tell their stories of the experience of caring for a dying patient in the general
medical-surgical unit. In the following section, a backdrop will be provided for the inquiry of the professional healthcare provider’s experience and perceptions of caring for the hospitalized dying patient in a non-ICU setting.

**Background and Significance**

The way people die in America has changed in the past 100 years. In 1900, people often died a quick death at home from an acute illness or accident; the family assuming the burden of care and expense. The average life expectancy has increased from 47.3 years in 1900 to 77.3 years in 2002 (Arias, 2004). Now, seventy percent of all deaths in the United States are in individuals age 65 or older (Coyle, 2001). Regrettably, living longer does not always equate with living a better life because most deaths today occur after a long, progressive and debilitating illness; only about 10% of all deaths are sudden (Robeznieks, 2003). The National Center for Health Statistics (2003) states that over eleven million deaths occurred in the hospital and only about a half million were at home in 2003 even though over 87% of those surveyed by Tang (2003) would prefer to die at home. Since most end of life care in the 21st Century is provided in hospitals by healthcare providers instead of family, it is important to examine the healthcare providers’ experiences in caring for dying hospitalized patients. The following sections elaborate the background and significance of the changes in dying.

**The Quest to Avoid Aging and Death**

The rapid pace of advances in biomedical sciences has constructed the view of natural aging to be pathological; medical interventions are often considered to be the correct and only tool for “managing the problems of aging” (Kaufman, Shim, & Russ, 2004, p. 721). This biomedicalization of aging has fostered society’s negative view of growing older and a belief that the effects of aging and eventual death can be avoided (Kaufman et al., 2004). American society does not view death as a normal part of the life cycle and financially supports
technologically complex and expensive healthcare costs through programs such as private insurance and Medicare without much direct cost to the patient or their family. What used to be extraordinary care (such as ventilators and artificial tube feedings) has become routine care to avoid death at all costs (Byock, 2004). The medical model of care that hospitals utilize is disease focused and views death as a failure (Byock, 2004). How does this attitude about death influence the healthcare providers’ experiences when caring for a patient who is dying?

**End of Life Care in the Hospital**

Frequently, the hospital becomes a revolving door in the last year of life, with each acute crisis weakening the patient and decreasing quality of life (Lorenz et al., 2004). Healthcare providers observe the patient’s decline and suffering with each episode of hospitalization, despite excellent and technologically advanced care. Many patients receive complex and expensive medical treatments that often do not cure and may have serious side effects that can compromise quality of life (Bailey et al., 2005). Numerous studies support the opinion that dying in the hospital does not equate to a “good death”. The often cited, Study to Understand Prognosis and Preferences for Outcome Risks of Treatments (SUPPORT) confirmed that there were considerable deficiencies for gravely ill hospitalized patients and they often received many intensive interventions in the last days of their lives (SUPPORT Principal Investigators, 1995).

Much of the recent literature about end of life care suggests that dying patients are receiving inadequate and inappropriate care in acute care hospitals (Middlewood, Gardner, & Gardner, 2001). Many patients suffer with unrelieved pain and symptoms while they die in the hospital (Byock, 1995; Field & Cassel, 1997; Goodlin, Winzelberg, Teno, Whedon, & Lynn, 1998; Meltzer & Huckabay, 2004; Shugarman, Lorenz, & Lynn, 2005). Research has shown that end of life care in the hospital may not be properly managed, even with technology and expert
medical and nursing care and that there are many barriers to quality care (Bakitas & Daretany, 2006; Casarett, Karlawish, & Byock, 2002; Yabroff, Mandelblatt, & Ingham, 2004).

**Barriers to Quality End of life Care**

Researchers have identified “substantial societal, healthcare system, provider and patient barriers” in quality end of life care (Yabroff, Mandelblatt, & Ingham, 2004, p. 202). Some of these barriers identified are:

- Societal and cultural views of illness, death and dying
- Organizational (limited availability of services such as palliative care and hospice and continuity of care)
- Healthcare provider issues (poor communication and inadequate education in attitude, knowledge and skills)
- Financial (inadequate reimbursement or insurance)
- Legal and ethical issues
- Inadequate research (Casarett et al., 2002; Yabroff et al., 2004)

It is not known how these barriers and other issues can influence the experience of the healthcare provider or professional caregiver due to the scant research.

**Societal and cultural influences**

The American culture has been described as “death defying” because it has accepted medical science’s ability to prolong life but finds acceptance of death as a natural process as “offensive” (Egan & Labyak, 2006, p. 40). Society views people who die as the victim of death and denies that death is a natural part of life (Connor, 1994; Kastenbaum, 1977). Society’s views of death are often shared by healthcare providers. Death can be viewed as a failure by the healthcare team, especially physicians, resulting in a reluctance in ending life sustaining treatment (White, Coyne, & Patel, 2001). This focus on cure and technology and not the whole patient and family has prevented individuals from living until they die. Treatments and tests are
offered even though they are not curative; symptoms are often minimized or ignored (Gruenewald & White, 2006). Americans and their medical team tend to create an atmosphere of combat in the fight to avoid death instead of acceptance as a natural trajectory of illness and aging (Komaromy, 2004).

Frequently end of life care is delivered and funded with an “either-or dichotomy that forces patients and their care providers to choose between life-prolonging and palliative models of care” (Casarett et al., 2002, p. 4). The perception of many patients, families and healthcare professionals is that to change the focus to palliative care is giving up, in fact the physician may tell the patient “there is nothing more we can do.” Referrals to hospice or palliative care services are not made until the patient is actively dying after weeks of futile aggressive treatments (Casarett et al., 2002).

**Organizational issues**

The goal of the hospital is to get the patient well enough for discharge in the shortest amount of time because reimbursement for costs of each admission is predetermined by Medicare based upon the diagnosis. The focus of acute care hospital is to deliver high quality technical care; patient requiring comfort or less acute care are usually transferred to other facilities such as hospice or long term care. The philosophy of providing comfort or palliative care in an acute care hospital is slowing gaining momentum, but is frequently underutilized.

Staffing patterns can be another issue in acute care. Frequently, the nursing to patient staffing ratio is calculated based upon the acuity (or high-tech interventions) of the patients (Aiken, Clarke, Sloan, Sochalski, & Silber, 2002). Nurses who work in the critical care units are assigned 1-2 patients, but the nurse in the medical-surgical unit may have 4-8 patients assigned to them. Dying patients who need only supportive care sometimes may be transferred to the general medical surgical unit to die if hospice care is not an option. Patient acuity is based upon
tasks and the amount of technical or skilled tasks that are needed. A lower acuity rating of the dying patient who needs supportive care only will reduce the amount of time the nurse can spend with the individual patient and family due to the needs of the other patients in his/her care. Frustration can develop, increasing stress when a healthcare provider is not able to deliver quality care due to lack of resources or time (Oberle & Hughes, 2001).

**Healthcare provider issues**

Lack of communications between the providers, patients and families are a major barrier to quality end of life care (Yarbroff et al., 2004). Difficult or uncomfortable subjects can be avoided by providers with excuses of not enough time (Byock, 2004). Sometimes healthcare providers, like their patients, deny that death is coming. Frequently discussions about death do not happen until death is imminent (Glaser & Strauss, 1965). Many physicians find it very hard to inform the patient that their disease will lead to death because they are afraid that this knowledge will take away hope (von Gruenigen & Daly, 2005).

The education in medical and nursing schools has failed to provide adequate preparation in the knowledge, attitudes and skills necessary to care for the patient at end of life (Jones, Garg, Bali, Yang, & Compton, 2006; Wakefield, 2000). Lack of education and understanding of the pharmacological effects of medications can also prevent quality care (White et al., 2001). Physicians and nurses, due to their inability to evaluate the pain, may not offer or administer adequate pain medications because they are afraid of overdose and giving a dose that causes the patient to die (Fink & Gates, 2006). Also there may be a fear of addiction with the use of opioids by both patients and healthcare providers, even though numerous studies show that opioids do not cause addiction when given for pain (Fink & Gates, 2006). Professionals who are not accustomed to caring for the dying may fear administering the last dose of an opioid may cause the patient to die.
The literature does support that increased stress can cause burnout in the healthcare provider and caring for the dying patient is stressful (Cohen-Katz, Wiley, Capuano, Baker, & Shapiro, 2004; Corley, Minick, Elswick, & Jacobs, 2005; Goodman & Boss, 2002; Meltzer & Huckabay, 2004; Oberle & Hughes, 2001). Burnout can lead to compassion fatigue and turnover in staff (Goodman & Boss, 2002; Maytum, Heiman, & Garwick, 2004). Employee turnover can affect the quality of care a patient receives; this can lead to a further exodus of staff from low morale due to staffing shortages. The environment can contribute to burnout; the hospice/palliative caregiver experience literature supports that the climate of holistic and ethical care of the patient and family aides in the reduced stress and burnout of the workers (Vachon, 1999). Little is known on how the hospital healthcare provider deals with the barriers to quality end of life care.

In the medical surgical unit, the nursing assistant has more contact with the patient and delivers more hands-on care than professional staff but there are no studies on the hospital nursing assistant experience in the literature reviewed. The nursing assistant is the least educated of the healthcare providers and is the primary provider of personal care and less technical care for the patient. There is a shortage of nursing assistants and turnover is common (Fitzpatrick, 2002). Since the nursing assistant is frequently the entry role into professional healthcare, we need to know how the death of a patient affects them and examine the effects of this experience on them in an effort to reduce turnover and retain them in the healthcare field.

Financial issues

The current reimbursement policy of Medicare does not pay for comfort care in the hospital or nursing home. Frequently hospitals lose money while aggressive treatments are continued long past the allowable reimbursement amount. Fischberg and Meier (2004) write that palliative care services must often be funded from other sources such as philanthropic or
institutional support for care that would otherwise qualify for the Medicare hospice benefit if the patient was in hospice not the hospital.

Legal and ethical issues

Healthcare professionals “have become more conscious of the complexity of the moral problems which can be created by caring for other people” (Randall & Downie, 1996, p.1). The patient has the right for self-determination or autonomy. Autonomy has become the highest ethical principle or a “supervalue” (Taylor, 1998, ¶ 4). The Patient Self Determination Act in 1990 and the Danforth Amendment, passed in 1991, require federally funded United States healthcare institutions to inform patients of their right to refuse treatment and to specify what treatments they wish by advanced directives (Bennahum, 1996; Teno et al., 2000). Often advance directives are unavailable. It can be difficult to determine what the patient would want when they are unable to speak for themselves and aggressive life-prolonging interventions are initiated automatically (Byock, 2004). An ethical conflict can occur if a patient, family and/or the physician wishes to continue painful and/or harmful treatments that are not likely to cure to do everything at all costs to sustain life. Futile interventions in the dying patient often can prolong suffering and only delay eventual death (Meltzer & Huckabay, 2004).

Other ethical principles can cause disagreements at end of life. Sometimes it is difficult to decide which is more harmful, the treatment or the disease. The medical culture that exists today promotes doing everything to prolong life unless the patient has specific instructions otherwise. The ethical principle of non-maleficence (do not harm) does permit the physician to withhold aggressive, painful treatments to prolong life if the treatment is deemed harmful or increases the patient’s suffering, but it is seldom applied (von Gruenigen & Daly, 2005). Many physicians have difficulty transitioning from curative treatments to supportive palliative interventions as evidenced by many patients receiving aggressive treatments and chemotherapy in the last days of
their life (von Gruenigen & Daly, 2005). The physician, by withholding the poor prognosis, believes that this is beneficence (doing good) because he/she is afraid the truth will take away hope (Mueller, Hook, & Fleming, 2004). Often ethical principles can be at odds, creating ethical dilemmas. These ethical dilemmas do create moral distress for the healthcare providers and may contribute to increased staff turnover (Meltzer & Huckabay, 2004; Mueller et al., 2004).

**Inadequate research**

Most of the professional literature on end of life care has focused on the patient and family’s experience. In 2004, the National Institute of Nursing Research (NINR) with the Agency for Healthcare Research and Quality (AHRQ) convened a State-of-the-Science Conference to evaluate the current research and clarify research priorities in end of life care and outcomes. This conference concluded that although evidence supports “the association of satisfaction and quality of care with pain management, communication, practical support and enhanced caregiving” at end of life there is ample opportunity for future research to increase the evidence base for end of life care and to improve outcomes (Lorenze et al., 2004, p. 5).

**The Purpose**

America is facing a crisis in the shortage of healthcare providers (Fitzpatrick, 2002; "Nursing shortage continues," 2006; Romano, 2006). It is necessary to understand the experiences of the healthcare provider so that changes such as education and support can be implemented to preserve the present staff. Diminished job satisfaction can be a reason employees leave a healthcare position; if we can learn from the healthcare provider as they tell their stories perhaps stressors and dissatisfiers can be identified ("Nursing shortage continues," 2006, p. 8).

This dissertation explores the experiences and perceptions of healthcare providers (physicians, nurses and nursing assistants) who cared for dying patients in general medical-surgical units by allowing the providers to tell their personal stories and utilizing narrative
analysis, a method of narrative inquiry. It is important to understand the providers’ perceptions’ of the experiences to identify barriers and obstacles that prevent delivery of excellent end of life care in the acute care hospital. The insights gained from this study provide evidence to suggest changes to support the staff in the delivery of excellent end of life care.

**The Research Questions**

The following research questions are addressed:

1. What are the experiences of healthcare providers (physicians, nurses and nursing assistants) when caring for a patient in the last 24 hours of life?

2. How do these experiences influence the healthcare providers’ view of their roles as professional caregivers?

3. How do the perceptions of the experiences differ among different disciplines or roles of the healthcare providers?

This study explores healthcare providers’ experiences as part of a multi-disciplinary team who are caring for patients at end of life in medical-surgical units, not ICU or oncology. Ramirez and colleagues (1998) suggested that there is little information on the healthcare professional that cares for patients with incurable disease as only a part of their workload. This study contributes to the knowledge base of the dimensions of professional caregiving by allowing the participants to describe their experiences by telling their personal story.

**Theoretical Perspective**

This qualitative research study is conducted in the interpretive, humanistic and naturalistic philosophical tradition. This study explores the experiences of healthcare providers (participants) caring for dying patients from their own personal story or narrative. The epistemological assumption is that the researcher interacts with the participant to gather data with semi-structured interviews. The interviews were conducted in an environment in which the participant was comfortable to encourage dialogue (Jacox, Suppe, Campbell, & Stashinko, 1999). The researcher
sought to describe the experiences and perceptions to understand the individual meanings of
caring for a patient at end of life within different contexts (Jacox et al., 1999).

For this dissertation, I employed Riessman’s (2002) theory of narrative analysis (See
Chapter 3). In narrative analysis, the “object of investigation” is “the story itself” (Riessman,
2002, p 218). This method draws from Labov’s structure to help interpret the meaning of the
story. The structure is what holds the narratives together or becomes the plot. Riessman’s method
of narrative analysis is divided into five levels of interpretation (See Chapter 3, Figure 2). Each
level is a snapshot; the interpretation changes at the junctures or levels. The levels of
representation helps the researcher to take a timeout and become more “conscious, reflective and
cautious” about the claims that are made (p. 229). Interpretations of the participant’s experience
were made using the method of narrative analysis based upon narrative theory. The following
section details how this method was utilized.

The Plan

After obtaining Institutional Review Board approval from the University of Florida and
Mayo Clinic, potential participants (physicians, nurses, and nursing assistants) were gathered by
referral of nursing management or other participants who met the criteria that they cared for a
patient within 24 hours of death in a medical-surgical unit. This is Riessman’s first level of
representation or Attending to Experience. An effort was made to select participants from each
role who cared for the same patient. I contacted the providers and invited them to participate and
if they agreed, conducted in-depth, face-to face, semi-structured individual interviews (See
Appendix A for Interview Guide).

The performance of the participant’s experience is the second level of representation, or
Riessman’s Telling About Experience. The interviews were audio taped and transcribed to
provide personal narratives that describes their experiences in caring for the dying patient. This
form of data collection or narrative inquiry allows the participant’s voice to be heard and through
the process of storytelling helped them identify their feelings and understand their actions or
meaning of the experience (Riessman, 2002). It is through this dialogue that their experience will
be explored to answer the research questions posed.

The third level of representation or Transcribing Experience is what the researcher
interprets from the text of the transcription and re-listening to the audio tape to hear “what do
they say?” (Czarniawska, 2004, p. 15). This process helped identify the boundaries of the
narrative segment. The transcription was re-transcribed to parse the narrative into numbered
lines. Each transcript was interpreted by the researcher to expose the “plot” of the narrative. This
is an interpretive process, the way the text is chosen to be displayed can be compared to cropping
a picture image; the interpretation changes with the view (Riessman, 1993). This process helped
the researcher examine for personal bias, by looking at the transcripts from multiple perspectives
or views.

The fourth level of representation is Analyzing Experience. During this period, transcripts
and analysis were reviewed with experienced qualitative researchers and members of the
researcher’s dissertation committee. The interpretations were discussed to provide multiple
views. The analysis continued through multiple rewrites and finally this dissertation. As you read
this completed dissertation, the fifth and final level of representation, Reading Experience is
achieved.

Summary of Plan. This method of narrative analysis using Riessman’s method guided me
in capturing, interpreting with different viewpoints, reporting the provider’s experience and in
comparing for similarities or differences in each person’s experiences. It allowed me to look
through the lens of the participants as they told their stories and to find meaning from their
experiences. The purpose of narrative analysis “is to see how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives….We ask why the story is told?” (Riessman, 2002, p. 218). The capturing of the lived experience as told in these “stories” allowed the participants to talk about caring for patients at end of life from their own perspectives in a very rich and diverse way and let me explore why the story was told. This methodical and intensive analysis of healthcare providers’ experiences caring for patients in the last 24 hours of life culminates in the presentation of this dissertation and provides evidence that these experiences are a significant event for these participants. In the following section I will discuss why this research contributes to the existing research in nursing.

**Research Significance to Nursing**

Research in end of life care is increasing, but there is much more needed. In the past decade, the Robert Wood Johnson Foundation has funded the landmark Study to Understand Prognosis and Preference for Outcomes and Risks of Treatment (SUPPORT) which confirmed a crisis in the quality of end of life care (Twohig & Byock, 2004). This study’s results revealed that many patients died in hospitals, isolated, on mechanical ventilation in intensive care units due to poor communication between patients and physicians (The SUPPORT Principal Investigators, 1995).

A study sponsored by the Institute of Medicine in 1997 identified the need for significant improvement in the way we care for people at end of life by increasing our knowledge in the delivery and financing of health and other services (Field & Cassel, 1997). This study also suggested further research was needed on the healthcare providers’ attitudes, skills and knowledge in caring for the dying. A recent search of the literature indicates that there is still a paucity of research in this area.
Past funding for research has traditionally focused on the prevention of death and supporting inpatient institutions and technology (Super, 2001). Most caregiver research has focused on the informal caregivers of patients with cancer or Alzheimer’s disease. There is a paucity of research on the professional caregivers’ experiences with the dying patients in the general medical-surgical unit. The majority of end of life nursing research focuses on the critical care, oncology or hospice nurse where death is common. There needs to be more research on the effects of caring for the dying when it is not routinely experienced by the provider (Ramirez et al., 1998).

The National Institute for Nursing Research (NINR) has also recognized the importance of supporting research in end of life issues and palliative care. In December, 2004, NINR and Office of Medical Applications of Research (OMAR) co-sponsored a conference to examine the state of the science of end of life care and identify needs for future research for “Improving Care at End of Life” (National Institutes of Health, 2004). Some of the conclusions reached at this conference included priorities to “conduct studies of caregiving in populations other than cancer and dementia” and “to evaluate economic and social dimensions of caregiving” (Lorenz et al., 2004, pp. v, vi). This study is a beginning step to address these caregiving experiences of healthcare providers who cared for a patient that died in a non-critical care area. The findings were compared with other studies from critical care and will add to the body of knowledge about the caregiver’s perception, stress and experience of caring for a dying patient. This knowledge can be used to develop supportive measures for the staff to decrease the stressors. It also identified information that will assist the healthcare provider in caring for a dying patient in an area that is less frequently a part of their daily duties.
The narrative derived from the interpretation of the participant’s narrative will provide a foundation for future studies such as grounded theory or quantitative theory testing and possibly validate the existing research (See Chapter 2 for summary of literature review) on the stresses of healthcare providers caring for the dying (Pope & Mays, 2000).
CHAPTER 2
REVIEW OF LITERATURE

Introduction

Current end of life research has focused on physicians and nurses who exclusively care for cancer, hospice and palliative care patients or patients in intensive care units; there is a paucity of research on the healthcare provider who cares for the dying patient in the general medical-surgical unit/ward of a hospital. No studies were located that featured the nursing assistant in an acute care hospital caring for a patient at end of life. Many factors can influence a healthcare provider’s experience while caring for patients and families at end of life. Discussion in this chapter will highlight the current published research and scholarly literature on negative and positive effects and the lack of preparation of the healthcare providers in caring for patients at end of life in the acute care and hospice environments.

Effects of Caring for the Dying on the Health Care Provider

Much of the research has converged on negative effects of caring for a dying patient such as stress\(^1\), burnout\(^2\), compassion fatigue\(^3\) and ethical or moral distress\(^4\). Researchers have shown that hospital employees face extraordinary stresses in their work environment from multiple causes (Marino, 1998; Ramirez et al., 1998; van Staa, Visser, & van der Zouwe, 2000). There is an increased incidence of stress, compassion fatigue or burnout in healthcare providers when

\[^1\] Stress: Body or mental tension resulting from factors that alter an existent equilibrium (Mish, 2000)
\[^2\] Burnout: Physically and emotional exhaustion, lack of motivation as a result of prolonged stress and frustration and overwork (Mish, 2000)
\[^3\] Compassion fatigue: Giving more energy and empathy than receiving. Symptoms are physical, emotional and spiritual exhaustion (Mulligan, 2004)
\[^4\] Ethical or moral distress: A state of disequilibrium when one is unable to do what is ethically or morally right because policies, rules or laws prevent the action (Meaney, 2002)
caring for the critically ill or dying patients in acute care hospitals (Aiken et al., 2002; Alexander & Ritchie, 1990; Andre, 2002; Badger, 2005).

Healthcare providers’ perceptions of their experiences are influenced by societal views, organizational structure of healthcare and hospitals, personal factors and ethical and moral issues. This section examines the healthcare providers’ experiences and how they are influenced by society, organizational structure, personal factors and ethical/moral issues.

Society’s Influence – Denial of Aging and Death

In the seminal work, *Awareness of Dying*, Glaser and Strauss (1965) wrote that Americans were “unwilling to talk openly about the process of death”, yet “death is one of the characteristic features of human existence” (p.3). They wrote that Americans and professional healthcare providers have the moral attitude that “life is preferable to whatever may follow it, and one should not look forward to death unless he is in great pain” (p.3). This moral attitude continues to influence care at end of life 40 years later as evidenced by what was once considered to be extraordinary care, such as mechanical ventilation and artificial nutrition and tube feeding, is now routine care (Byock, 2004). The medical successes that prolong dying may actually allow death to become more hidden in American society (Webb, 1997). Mass media perpetuates society’s denial that aging and death are natural transitions of life. The media has influenced the public’s perception that medicine has the ability to prevent aging and death (Yabroff et al., 2004).

Society views people who die as *the victim of death* and denies that death is a natural part of life (Connor, 1994; Kastenbaum, 1977). This view can also influence the healthcare provider to deny or not recognize that the patient is dying, until after a number of aggressive medical interventions fail, causing distress in the professional caregiver (Smit, 2005). Because society denies that we age and die, there can be a stigma related to caring for patients who are dying.
Research indicates that the health care provider may have feelings of guilt and question care at end of life, as revealed in a qualitative/grounded theory study of physicians by Ruopp and colleagues (2005). The physicians studied said they questioned care more often in deaths that they were affected emotionally than they did in the most recent death of a patient.

There is uncertainty in death; it is very difficult to predict when it will happen even in the face of terminal illness (Glaser & Strauss, 1965). The patient may feel that to acknowledge that they are dying and to talk about it will disappoint the doctor or their family because they are giving up; so often they suffer in silence. Field and Cassel (1997) believe that patients suffer because hospitals focus on a medical model of care of curing disease and prolonging life. The battle to cure the disease becomes the focus, not the painful feelings that are buried deeply by the patients, family and also in the healthcare providers. Precious healing time is lost during this dance of avoidance when a cure is no longer possible due to society’s influence to deny death (Quill, 2002).

There has been a recent trend in hospitals to provide palliative care in response to improve the care a patient receives at end of life (Fischberg & Meier, 2004). “Palliative” is defined by Taber’s Cyclopedic Medical Dictionary (2001) as “relieving or alleviating without curing” (p. 1559). Palliative care or comfort care is holistic and considers the family and the patient as the unit of care and should be offered at time of diagnosis of a chronic or terminal disease (Fischberg & Meier, 2004). Unfortunately, due to society’s influence, the perception of many patients, families and healthcare professionals is that to change the focus from curative to palliative care is giving up, in fact the physician may tell the patient “there is nothing more we can do” when they suggest hospice or palliative care. Referrals to hospice or palliative care services are often not made until the patient is actively dying after weeks of futile and aggressive treatments (Casarett...
et al., 2002). Palliative care is also the model of care that a patient receives in hospice. Hospice and palliative care does not deny that death will come; it focuses on living, not illness, through expert symptom management to promote healing. Society’s denial and lack of acceptance of death as the natural continuum of living also influences the organizational structure in hospitals and other healthcare settings and the experiences of the healthcare provider.

**Organizational Structure Factors**

The deficiencies in the organizational structure of the healthcare system have been correlated with stress and burnout of healthcare workers (Badger, 2005; Corley et al., 2005; Davidson et al., 2003; DelVecchio Good et al., 2004; Dodd-McCue & Tartaglia, 2005; Goodman & Boss, 2002; Mackereth, White, Cawthorn, & Lynch, 2005; Marino, 1998; Maytum et al., 2004; McNeely, 1996). Research focusing on nurses has shown that burnout occurs when the nurse does not have the resources to meet the patient’s needs or cannot cope with feelings of stress (Meltzer & Huckabay, 2004). Nurses complain of overwork and limited resources (Maytum et al., 2004; McNeely, 1996). Hospitals have been faced with increasing financial pressures due to rising costs and limited reimbursement, which in turn, limits the availability of services and staff (Yabroff et al., 2004). When burnout becomes too much, absenteeism increases due to physical illness and emotional exhaustion; employees may leave the organization to cope (Goodman & Boss, 2002). Employee turnover is very expensive; it can be greater than 5% of a hospital’s already tight operating budget (Waldman, Kelly, Arora, & Smith, 2004). When there is high employee turnover, stress increases, morale is poor and patient care suffers.

The nursing literature has featured many studies on stress and burnout in hospitals since the 1970’s. Chronic stressors and a perceived lack of control in the workplace can be exemplified by physical and emotional distress (Sitzman, 2004). Nurses often have little control or autonomy
in their practice and may feel impotent (Cohen-Katz et al., 2004). Staff shortages and heavy workloads may contribute to burnout and turnover in hospitals. Burnout can cause nurses to leave their profession entirely, thus creating more shortages and increased burnout of those left behind. Sumner and Townsend-Rocchiccioli (2003) suggest that nurses are leaving the profession because they feel trapped between hospital bureaucracy and the patient and/or the physician and the patient; they find it very difficult to perform their duties due to these obstacles. Nurses feel that they are not valued and that they are a commodity instead of an asset to hospitals. Sumner and Townsend-Rocchiccioli also believe that nurses need more recognition as they cope with human crisis in their everyday workload, caring for patients at end of life is a human crisis.

The structure of the hospital’s work environment and lack of clear guidelines has been identified by researchers as an obstacle in providing optimal patient care because it affects the working relations of doctors and nurses (Nordgren & Olsson, 2004). Lack of guidelines and protocols can generate uncertainty and this creates stress and anxiety in the healthcare provider. Dodd-McCue and Tartaglia (2005) found that a clear protocol for organ donation reduced uncertainty and perceived stress in critical care nurses when caring for the dying patient.

Disagreements among the patients, families and staff can cause conflict in the work environment, creating stress. Patients and their families may have unrealistic expectations; physicians found it stressful when expectations differed between themselves and the patient-family unit (Farber, Egnew, Herman-Bertsch, Taylor, & Guldin, 2003). Nurses in a medical intensive care unit identified conflict with families as a source of stress (Badger, 2005). There may be disagreements about the efficacy of a treatment or lack of symptom management among staff (Vachon, 1986). Anselm and colleagues (2005) found in a qualitative study of Canadian
nurses and doctors that there were barriers to good communication and resulting disagreements were major impediments to quality end of life care. Four main categories were identified, “(1) patients, (2) the healthcare system, (3) healthcare providers, (4) the nature of the dialogue” (p. 214). The researchers concluded that the physicians and nurses “perceived the recipients of their care, and the system within which they provide care, to be the major source of barriers to communication regarding end of life care” (p. 215).

Healthcare organizations can implement measures to reduce the effects of stress in healthcare workers. One of these ways is to foster a culture of caring and healing, not only for the patients but also for the staff. For example, when a hospital shows that it cares for its staff, this helps enable the staff to improve care for the patients at end of life (Felgen, 2004). Improved patient care and comfort can help prevent the burnout or compassion fatigue and improve the quality of care that patients receive (McNeely, 1996). Mackereth and colleagues (2005) suggest that complementary therapies such as massage, counseling and clinical supervision can assist staff to manage the stress in their work. Others have suggested techniques such as mindfulness-based stress reduction, which emphasizes self-care, compassion and healing, which can be taught to help manage stress and reduce burnout (Cohen-Katz et al., 2004). Debriefing or a forum in which the staff can come together to discuss their experiences, thoughts, and feelings after the death of a patient helps improve the staff’s relationships and can reduce stress and anxiety (Bishko, 2005). Glaser and Strauss (1968) described how nurses and physicians found resolution when a patient died by telling stories about the experience.

**Personal Factors**

We are our past, present and future. Healthcare providers’ perceptions of the experience of caring for a patient at end of life are shaped by past personal experiences, personal philosophy, culture, spirituality and education or training. Past experiences with loss and death affect the
caregiver’s experience when a patient dies. Connor (1994) writes that providers “can only be effective in helping others face death” when they “have explored and confronted” their own mortality (p. 166). Borneman & Brown-Saltzman (2001) write that a healthcare professional must live out the experience of caring for patients at end of life to find meaning and understanding. If the provider identifies with the patient or family, the impact on the individual can be greater, causing more emotional distress with intense feelings of loss and grief. For example, from my personal experience as a hospice nurse, I found it very difficult to attend the death of a male patient on the first Father’s Day after my father had died. It is important that healthcare providers communicate their needs and recognize their own limitations when caring for the terminally ill. Studies show that grief is painful and requires much emotional energy over time as the healthcare provider copes (Marino, 1998). One study found that 50% of physicians who cared for terminally ill patients experience burnout from grief related job stress (Redinbaugh, Schuerger, Weiss, Brufsky, & Arnold, 2001). The demands of the role of a caregiver who experiences grief when a patient dies can lead to compassion fatigue due to the emotional drain and burnout of caring for patients and families at end of life.

Compassion fatigue is described as a form of burnout that can negatively affect caregiving (Sherman, 2004) when more energy and compassion is given out than received, resulting in spiritual, emotional and physical exhaustion (Mulligan, 2004). Compassion fatigue is also called secondary traumatic stress when a traumatizing event is witnessed or heard about someone who is significant. Nurses and other healthcare workers who identify with patients or their family have a greater risk to suffer compassion fatigue when the patient dies because they may become more aware of their own losses and aware of anxiety from death awareness (Marino, 1998).
Several studies also indicate that physicians can suffer from burnout and compassion fatigue when caring for the terminally ill (Graham et al., 1996; Redinbaugh et al., 2001; Weiss, 2003).

The healthcare provider’s personal experiences with death can affect the quality of care a dying patient receives. Providers, who are uncomfortable with death, may treat the patient in a very impersonal, task oriented manner. McNeely (1996) noted that more than half of the nurses surveyed who worked in palliative, psychiatric and general nursing areas coped with stress by denial, avoidance or distancing strategies, but less than one quarter found it helpful with the stress they experienced. Physicians often focus on the disease process in order to try and maintain “control” instead of recognizing that they cannot cure everyone (Price & Bergen, 1980). Some providers may linger at the bedside and feel helpless that they are not doing enough when a patient is imminently dying. Others may use distancing, humor and rationalizations to help themselves cope (Palmer, 1983).

Lack of education and training for healthcare providers has been identified as a deficiency in providing quality end of life care (Casarett et al., 2002). In 1965, Glaser and Strauss stated that physicians and nurses are taught the technical aspects of caring for the dying, but not how to communicate with the dying patient. Many nurses still feel that they are not adequately prepared to care for the dying (White et al., 2001). Davidson and colleagues (2003) conducted focus groups with cardio-respiratory nurses and identified four themes about caring for patients at end of life:

- searching for meaning in the dying experience of patients with chronic disease
- lack of treatment plan and a lack of planning and negotiation
- discomfort in dealing with death and dying
- lack of awareness of palliative care philosophies and resources (p.47)

These findings indicated that a lack of knowledge in how to provide palliative care to patients with non-malignant end stage disease was prevalent in this nursing population.
End of life education initiatives for physicians and nurses have been increasing in both basic and continuing education. Two such programs are Education for Physicians on End of Life Care (EPEC) and End-of Life Nursing Education Consortium (ELNEC). Williams and colleagues (2005) found that end of life curriculums should incorporate teaching coping strategies and provide a means of reflection by medical students to help them recognize and think about their feelings. Curriculums that include the writing of narratives has been shown to give the student a way to reflect, process and express strong emotion of caring for the dying (Wessel & Garon, 2005). The use of narratives and reflections in the education of the homecare palliative care nurse helped the nurse acknowledge their feelings and can show the educator ways to improve the curriculum to help the student cope with difficult experiences.

**Ethical and Moral Factors**

Emotions are intense at end of life which can lead to moral distress in the healthcare provider. Moral distress can occur when there is a conflict about values or when one feels that one way is morally right, but does not or is unable to follow through (Meaney, 2002). Corey et al (2005) described moral distress “as painful feelings and/or the psychologic disequilibrium” that happen when the healthcare provider is “consciously of the morally appropriate action a situation requires but cannot carry out that action because of institutionalized obstacles” (p.636). Organizational factors can create moral distress because the provider may not perform their duty in a manner that is morally appropriate because of impediments due to time restraints, deficient supervisory support, policy or legal limits (Corely, 2002).

In instances where futile or overly aggressive measures serve to only prolong the dying process, studies show that the healthcare providers suffer from increased stress and moral distress (Badger, 2005; Davidson et al., 2003; Mackereth et al., 2005; Smit, 2005). Others have said that it is healthcare’s focus on curing the disease with futile and possibly hurtful
interventions and not viewing the patient as a holistic person that create stress in the professional provider (Cohen-Katz et al., 2004; Goodman & Boss, 2002; Meltzer & Huckabay, 2004; Sherman, 2004; Sitzman, 2004; Vachon, 1999). Nurses and physicians have expressed concern over the over-use of life-prolonging extraordinary treatments such as mechanical ventilation, dialysis and cardiopulmonary resuscitation and the patient’s right to choose these measures (Galanos, 2004). Meltzer and Huckabay (2004) found that the perception of futile or non-beneficial patient scenarios had a significant relationship to emotional exhaustion which can lead to burnout. When these extraordinary measures are applied regardless of what the patient would want, the healthcare provider may experience moral distress. Moral distress leads to frustration, anger or guilt which can cause healthcare workers to avoid relationships with patients and to even leave their profession (Corley et al., 2005).

The intense emotion at end of life requires that healthcare providers support one another (Wilt, 2001). But this is not always the case, research suggests that physicians and nurses see ethical problems in a different way and make decisions on different frameworks, creating conflict and misunderstandings (Oberle & Hughes, 2001; Randall & Downie, 1996). Communication among caregivers and the patient/family is imperative to foster an environment of mutual respect and caring.

**Positive Effects of Caring for Patients at End of Life**

Although the bulk of current literature on the healthcare professional that cares for the patient at end of life speaks about the negatives, past experiences can have a positive effect on the caregiver too. Nurses who cared for patients who had a near-death experience described that they were more comfortable talking about death to patients and families and that they became more sensitive to the unconscious patient (Morris & Knafl, 2003). Some caregivers reported feelings of empathy and self-fulfillment when caring for the dying (Smit, 2005). Ramirez and
colleagues (1998) also suggest that the stress of caring for dying may actually be "counterbalanced by the satisfaction of dealing with patients and relatives" in healthcare professionals who work full time with the dying such as in hospice or palliative care (p.2). The literature does not adequately address why some people choose to care for the dying patient and why they find the experience positive and rewarding. More research is needed to understand the experiences of the healthcare providers caring for the dying patient.

**Summary**

In this chapter, the literature was reviewed for evidence of the effects of caring for the dying on the healthcare provider as it relates to societal influences, organizational structure of healthcare and hospitals, the provider’s own personal factors and ethical and moral issues. The reviewed literature suggests that the healthcare providers’ experiences caring for patients and families at end of life are largely negative because of the extreme stress the providers endure. Compassion fatigue, stress and burnout are common themes in the current and past research.

Societal factors that can contribute to negative experiences of healthcare providers are related to the media’s portrayal of aging and death as unnatural which in turn can stigmatize those who care for the dying. Death is often not discussed openly because the medical model of care practiced in hospitals is to cure disease and prolong life. Today’s medical technology can allow patients to die slowly and painfully attached to machines that provide vital functions that the body can no longer perform. Societal influences can cause patients and their families to refuse palliative care because it is viewed as “giving up” which in turn contributes to prolonging the dying process. Often patients, families and healthcare providers focus on battling the disease and do not acknowledge feelings or talk about them, which results in loss of precious time that could begin to heal the psyche and help with grieving.
Organizational structures of the hospital such as financial pressures and staffing patterns has been correlated with stress and burnout of healthcare workers. If the necessary resources (which can include supplies and staff) are not available, it can contribute to physical illness and emotional exhaustion of the healthcare provider. Hospitals may not acknowledge that caring for patients is a human crisis in the healthcare providers’ everyday workload causing nurses to feel that their work is undervalued. Lack of protocols or clear guidelines can create uncertainty and can be an obstacle to communication between healthcare providers creating increased stress and anxiety.

Personal factors influence the healthcare provider’s perception of the experience of caring for a patient at end of life. The literature suggests that past personal experience in death, philosophy of life, culture, spirituality and education or training influence perceptions of experiences. How the provider copes with emotions they may feel after caring for the dying is often how they find meaning and understanding of the experience. Identifying with the patient or family can accentuate the emotional distress a caregiver may experience. Emotional distress or unresolved grief can lead to compassion fatigue and or burnout. Coping strategies for stress caused by personal factors may contribute to poor patient care when the provider avoids or distances themselves from a dying patient. The healthcare provider may not realize that personal factors can affect the quality of care that they deliver and research literature suggests that education initiatives for nurses and physicians can improve care by teaching coping strategies and technical aspects of palliative care.

Ethical and/or moral issues are also problematic at end of life and can cause great emotional distress to the healthcare provider. If a provider feels that something is morally right, but is not supported by society’s views, organizational structures, patient’s family or other
caregivers, they can experience moral distress. Overly aggressive treatments which are viewed as futile or painful can lead to the provider to experience frustration, anger and guilt because they feel that the patient’s dignity was compromised. These feelings can cause a provider to leave their profession if they remain unresolved. Good communication among the providers and the patient and family is important to foster an environment of mutual respect and caring.

Although most of the literature I reviewed reflected mostly negative experiences for providers caring for patients at end of life, there were some positives. Nurses who cared for patients who had near death experience became more comfortable caring for the dying. Caring for the dying can provide satisfaction because the provider is also caring for the living, that is the patient who is still alive and their family. More research is needed to provide an understanding of why healthcare providers choose to continue to work with the dying patient and cope with the negatives of caring for patients at end of life.

Much of the funded research focuses on care of the patient and symptom management, but very little on the experiences of the physician and nurse who care for the patients in a general medical-surgical unit. Research on other team members (especially the nursing assistant) is minimal too. More research is needed to understand the experience of the healthcare provider and why they choose to continue to work with the dying, even when faced with stress, burnout, grief, compassion fatigue and moral distress. This dissertation is designed to explore these factors and identify others contributing to the experiences of healthcare providers in the medical surgical units while caring for patients at end of life. In the next chapter, I discuss my research method utilized to investigate the experiences of the participants of this study.
CHAPTER 3
RESEARCH METHODS

Introduction

Hoskins and Mariano (2004) state that research is necessary to build the science of nursing. Study design begins with the selection of questions that interest the researcher to address knowledge gaps and the application of a paradigm or philosophical approach of inquiry. The paradigm can be either quantitative or qualitative. In beginning of this chapter, I discuss interpretive qualitative research, narrative inquiry and narrative analysis. The chapter continues with the application of narrative analysis to my study.

The Qualitative Paradigm

Beck (1999) described the difference between quantitative and qualitative research as simply quantitative uses *numbers* and qualitative uses *words* as the source of information or data. The differences between quantitative and qualitative research are more complex than this simple definition. Qualitative research has its origin in the “behavioral and social sciences as a method for understanding of the unique, dynamic, holistic nature of human beings” and the qualitative researcher is “concerned with the understanding of the meaning of social interactions by those involved” (Burns & Grove, 2005, p. 24). The paradigm of qualitative research can be described as constructivist or naturalistic, interpretive and post-positivist or postmodern. The philosophical view of interpretive research will provide the paradigm for this study.

The interpretive qualitative researcher “tries to interpret social phenomena” (interactions, behaviors, etc.) (Pope & Mays, 2000, p. 3). Interpretive qualitative inquiry allows the researcher to not only gain knowledge about participants’ experiences, but to discover and examine how the researcher’s own experiences shape what is learned (Patton, 2002).
Qualitative research or inquiry is a systematic method used to explore human beings and their interactions within their environment or natural setting. Interviews and observations are conducted in the field or where the participants work or live. Qualitative inquiry is accomplished by building (constructing) a detailed and holistic view and analyzing (interpreting) the words of participants in their (natural) environment or where they are most comfortable (Creswell, 1998). Merriam (2002) states, “Qualitative researchers are interested in understanding what those interpretations are at a particular point in time and in a particular context” (p.4). This is done by simultaneous data collection and interpretation. Merriam also describes the interpretive qualitative approach as “learning how individuals experience and interact with their social world” and “the meaning it has for them.” (p. 4).

**The Use of the Qualitative Paradigm in this Study**

Interpretive qualitative research methodology was a good fit for this study because I was interested in how the healthcare providers made sense or found meaning from the experience of caring for dying patients and understanding how their role (nurse, physician and nursing assistant) influenced that experience. Creswell (1994) states that the qualitative method is appropriate when there is a lack of previous research; there has been minimal research on the experiences of healthcare provider who are caring for patients at end of life on the medical-surgical unit. No published research of the hospital nursing assistant’s experience caring for a patient at end of life was located utilizing electronic database search engines (Pub Med & CINAHL).

Participants who cared for a patient in the last 24 hours of life in a medical-surgical unit provided the data for this study. The interviews provided a discourse or narrative that allowed the participant to describe or tell their stories of caring for the dying from their own perspective. The researcher then constructs a new narrative from the data or stories told by the participants. The
use of narratives in qualitative research is narrative inquiry. The following section will discuss
narrative inquiry and narrative analysis.

**Narrative Inquiry**

Narrative inquiry is a subtype of qualitative inquiry (Chase, 2005). Narrative inquiry “focuses on how to interpret stories, life history narratives, historical memoirs, and creative nonfiction to reveal cultural and social patterns through the lens of individual experiences” (Patton, 2002, p. 478). The interest of using narrative inquiry in research has grown (Burck, 2005; Hoshmand, 2005; Jones, 2004). Narrative inquiry is truly interdisciplinary and resides well in the social sciences realm because of its interpretive approach. It has frequently been used as a method for medical research, anthropology, psychology, nursing and sociology. The spoken word or written text that tells a story is used for narrative inquiry.

Many different traditions of qualitative inquiry use narratives. The method of qualitative inquiry is dependent on the philosophical perspective or lens the researcher views the narrative. For example, Heidegger’s interpretive phenomenology seeks to understand the lived experience from the view of the concept or phenomenon utilizing an interpretive framework or hermeneutics (Steubert Speziale & Carpenter, 2003). Ethnography can also have an hermeneutic perspective looking at the culture by analyzing inferences and the implication of behavior (Steubert Speziale & Carpenter, 2003). Grounded theory seeks to develop substantive theory grounded in data by exploring “basic social processes” (Schram, 2003; Steubert Speziale & Carpenter, 2003, p. 118). Grounded theory is based in symbolic interactionism theory or that people act and react to others based on how they give meaning to symbols such as hair color or perhaps a wedding ring (Steubert Speziale & Carpenter, 2003).

Narratives can be both a data collection tool and “the result of the analysis of the telling of the experience in its entirety with great detail” (Overcash, 2003, p. 180). Narrative analysis
focuses on the whole story or plot, not lines of text taken out of context (Muller, 1999). When
the report is written at the end of a study and it tells a story, it also becomes a narrative. This
dissertation is my narrative of this study because it tells my interpretation of the stories of nurses,
physicians and nursing assistants who cared for a dying patient in a medical surgical unit of an
acute care hospital.

**Narrative Analysis as a Method of Narrative Inquiry**

The object of narrative analysis is the story or the plot. The plot is the structure or
organization of the narrative which clarifies the meaning of the events told (Polkinghorne, 1988).
It is the plot that makes the narrative a story. Storytelling is a communication tool used by
humans to convey messages and emotions to each other. Rodriguez (2002) stated, “We are
indeed narrative beings” and “we negotiate the world and our humanity through narratives”
(p.3). Narratives allow the storyteller to tell about their past actions and understand or find
meaning in the telling (Riessman, 2002). Stories are told by individuals, and the resulting
narratives are representations subject to interpretation by both the teller and the researcher.
Riessman (2002) states storytelling “is what we do with our research materials and what
informants do with us” (p.218).

Clandinin and Connelly (2000) write that narrative inquiry is three-dimensional,
“temporality along one dimension, the personal and the social along a second dimension, and
place along a third” (p.50). This study is a three-dimensional inquiry: the participants shared
their thoughts and feelings they experienced at the time they cared for the dying patient
(temporal), how their feelings and role influenced their behavior (personal and social) while
caring for the dying patient in a medical-surgical unit (place).

Narrative inquiry like all research has its foundation in theory. Narrative theory has birthed
many forms of narrative analysis (Burck, 2005). Choosing narrative analysis as a method
requires decisions about philosophy and methods, because it will affect the “understanding one will achieve” (Hoshmand, 2005, p. 179). It is important to understand the underpinnings of narrative analysis by examining the theory.

**Narrative Theory**

Theory provides a way for associated knowledge to be “articulated and organized into meaningful wholes” (Meleis, 1997, p. 17). Narrative theory has been shaped by history, society and cultural influences. The emergence of interpretive social sciences has changed the theoretical perspectives of the narrative in psychology and human sciences (Hoshmand, 2005).

Many theorists and philosophers have developed theories about narratives, evolving “from classical poetics to the postclassical, and from structural to more contextualist and functional models in the poststructural and postmodern period” (Hoshmand, 2005, p. 178). Mishler (1995), dismisses the belief that the study of narratives is “a separate and distinctive discipline” but “view[s] it as a problem-centered area of inquiry” (p. 88). The term narratology, or the study of the narratives, was first used by Todorov in 1969, because he wanted it to be recognized as a new science (Riessman, 2002). Narratology is described as a form of qualitative inquiry and data analysis that uses narrative theory (Hoshmand, 2005).

The constructs of narratives differ among the different disciplines. There is disagreement about defining narrative; it can be broad or very specific. *Merriam Webster’s Collegiate Dictionary* defines narrative as “the representation in art of an event or story, also an example of that representation” (Mish, 2000, p. 771). Narratives can be oral or written. A narrative can be simply telling about life and illness in medicine to being very structured with formal properties requiring “temporal and/or causal coherence in the meaning structure” as in literary or linguistic study (Hoshmand, 2005). Garro and Mattingly (2000) stated that exploring narrative as a construct or theory can provide a “broader context” for what took place in the telling of a story.
Labov (1972, p. 359) defines narrative as “one method of recapitulation of past experiences”. Aristotle believed the narrative has a beginning, middle and end (Labov, 1972; Riessman, 2002). Other scholars believe it should be chronological or move in a consistent way, so that the teller is “responding to the question, ‘And then what happened?’” (Riessman, 2002, p. 230). Narratives can construct reality, but they are open to different interpretations by the audience (Ricoeur, 1980). The audience can be the reader or listener. Stories are about events experienced by the actor (or narrator) which gives the audience the feeling of being in the story world of that reality (Garro & Mattingly, 2000). This dissertation uses the stories of the participants to address the research questions in an attempt to capture and understand their world or reality.

**The Research Questions**

I have chosen the framework of qualitative inquiry, narrative theory and narrative analysis to address the following research questions:

1. What are the experiences of healthcare providers (physicians, nurses and nursing assistants) when caring for a patient in the last 24 hours of life?

2. How do these experiences influence the healthcare providers’ view of their roles as professional caregivers?

3. How do the perceptions of the experiences differ among different disciplines or roles of the healthcare providers?

These questions are important because there is an insufficient body of knowledge about the healthcare provider’s experience and perceptions when caring for a dying patient and it has been well documented that care at end of life can be improved. The use of narrative analysis provides a method to understand the meaning and the experiences of caring for a dying patient from the stories the healthcare provider tells and capture their reality in the form of another narrative. Exploring the healthcare provider’s experience through the interpretive process of narrative
analysis can provide possible theories that can be developed and tested in future studies to improve the care of patients and the healthcare provider’s experience at end of life in the hospital setting.

**Study Design**

**Narrative Analysis – The Method**

Most published research on caring for patients at the end of life has focused on the nurse and physician in the intensive care or hospice/palliative care setting. Numerous studies have shown that care at end of life is deficient, but more knowledge is needed to understand the challenges and what the perceptions are of those caring for these patients in the acute hospital setting (Thompson, McClement, & Daeninck, 2006). The study design utilized in this dissertation research is exploratory using narrative analysis. Respondents were asked to tell their story about caring for a patient at end of life using an Interview Guide (See Appendix A). Narratives or the participants’ stories in this study are the medium for the describing their personal experience in caring for the patient at end of life. The analysis of the narrative is a way to capture, interpret and report on an individual’s experience and compare for similarities or differences in each person’s experiences. Narratives can also provide a medium to help individuals deal with difficult situations or to find meaning in the experience (Wessel & Garon, 2005). Narrative analysis is a good fit for this study because it allowed the researcher to look through the lens of the participants as they told their stories and found meaning from their experiences by a structured and systematic way in an interactive format with the researcher. It allowed the researcher to examine the stories of the nurse, physician and nursing assistant, interpret that experience and produce new narratives to report the findings of the healthcare provider’s story caring for a dying patient in a medical surgical unit. In the following sections the
The process of narrative analysis utilized in this study is detailed, beginning from the event or caring for the dying patient culminating to this dissertation.

**From the Event to Research – Narrative Analysis**

In my field of practice as a healthcare provider and nurse, I have observed storytelling by other healthcare providers as they talked about their experiences caring for their patients and families at end of life. In this dissertation I wanted to hone in on the specific experiences of healthcare providers who cared for patients in the last 24 hours of life in the medical surgical unit. Czarniawska (2004) conceptualized how the field of practice moves to the field of research using narrative analysis. The diagram below illustrates how my Field of Practice (Healthcare Provider) flows to the Field of Research (Dissertation) in a series of steps using Czarniawska’s model:

**Field of Practice (Healthcare Provider)**

- Watch how the stories are being made
- Collect the stories
  - Provoke story telling
    - Interpret the stories (what do they say?)
    - Analyze the stories (how do they say it?)
    - Deconstruct the stories (unmake them)
  - Put together your own story
  - Set it against/together with other stories

**Field of Research (Dissertation)**

Figure 3-1. Field of Practice to Field of Research (Czarniawska, 2004, p.15)
Although Czarniawska’s model illustrated how my field of practice could move to the field of research or my dissertation, it did not fully describe how narrative analysis is accomplished or how to interpret the importance and research significance of why the story is being told. Narrative analysis does not have a standard set of procedures like some other forms of qualitative analysis (Riessman, 2002). Riessman’s model of Levels of Representation in the Research Process provided an approach for me to conceptualize how I could analyze and interpret the stories of the participants in this study.

**Riessman’s Model of Levels of Representation in the Research Process**

There are five levels of Riessman’s model and she believes that at each level there is interpretation, and text is created at every stage, which causes the meaning to be ambiguous from the “process of interaction between people: self, teller, listener and recorder, analyst and reader” (p. 228). She describes “meaning as fluid and contextual, not fixed and universal” (p.228). Each process of representation level expands and reduces by what is interpreted and has meaning for the individual experience, some things are deemed important and are expanded, and things that are considered irrelevant are discarded. Riessman believes this process can facilitate “us to be more conscious, reflective, and cautious about the claims we make” (p. 229). Each level is described briefly below. Figure 2 is a pictorial representation of her model and shows how each level builds on the previous level.

- **Attending to Experience** – where the individual or participant of the study makes certain the experience is meaningful
- **Telling About Experience** – a performance of a personal narrative, meaning shifts to being a process of interaction
- **Transcribing Experience** – text from audiotape, an interpretive practice, meaning can shift in different ways, is based upon what is common knowledge
- **Analyzing Experience** – Editing the story to make it fit into the report, becomes a hybrid
• Reading Experience – Changes with the reader, what the reader brings with them influences the meaning they perceive (pp. 222-228)

Figure 3-2. Levels of Representation of Narrative Analysis

Riessman’s model of Levels of Representation provided the theoretical foundation and structure for my method in this study. This method is a very fluid process, it was necessary to constantly reassess and readdress each level/step during the analysis, for example at Level Four: Analyzing Experience, it is necessary to confirm that the experiences were meaningful to the participants before analysis is continued to achieve Level One: Attending to Experience. The application of Riessman’s method for this dissertation facilitated immersion into the data, but also allowed for examination and thoughtfulness at each different level. The following sections describe how the levels were applied as the method in this study.

**Level One: Attending to Experience**

The selection of participants who have cared for a dying patient embodies the first level of representation or *Attending the Experience* in narrative analysis; they have had the experience of
caring for a dying patient. In my nursing practice, I have observed nurses, physicians and
nursing assistants caring for patients at end of life or as Czarniawska (2004) describes
‘Watching How the Stories are Being Made’. In my role as nurse, the death of a patient had a
profound effect on me; I would tell the story to others to help process my feelings. I have also
noticed that my co-workers seemed to also have a need to share experiences that caused them
distress. These observations contributed to my interest as how a death of a patient in a medical-
surgical unit is processed by other healthcare providers and the conceptualization of the research
questions for this study. This study provided a vehicle to examine in depth the experiences and
roles of other healthcare providers who had cared for a patient in the last 24 hours of life.

Subject selection and recruitment

Institutional Review Board (IRB) approvals from both University of Florida and Mayo
Clinic to perform this study were obtained prior to beginning data collection. After IRB approval
the next step was to “Collect the Stories”. The setting of this study is the hospital that the
researcher was employed at time of data collection, an acute care hospital in North Florida.
Stratified purposive sampling procedures were used to invite participants. I spoke with each
potential participant to determine if they met criteria for inclusion for this study: that they had
cared for a patient in the last 24 hours of life in a medical surgical unit and that they were willing
to tell their story. An effort was made to recruit participants who have cared for the same patient
but in different roles in order to facilitate role comparisons and address Research Question #3.

Six participants were initially recruited and interviewed, two registered nurses, three
physicians and one nursing assistant. Nurse1, Nurse2 and Physician2 were individuals who I
knew from my nursing practice at the hospital, a 300+ bed acute care secular teaching hospital.
The other two physicians’ names were given to me by Nurse 2 and I telephoned them and asked
if they would agree to participate in the study. Nurse 2 also introduced Nursing Assistant 1 to me
and she agreed to partake in the study. These interviews were conducted late August 2007 thru mid January 2008.

Recruitment was suspended in January 2008 because of the impending change of ownership of the hospital and I also changed employer in January 2008 to stay at the hospital with the new management/owners. The hospital transformed into a community faith-based hospital with an average census around 110 in April 2008. There was much change and stress in the spring, summer and fall during and after this transition: new employees, new policy and procedures, staffing changes, philosophy, hurricanes and subsequent layoffs. The researcher resumed data collection in November and December 2008 after obtaining IRB permission from St. Vincent’s Healthcare and University of Florida to conduct interviews with the new ownership. The remaining two nurses and two nursing assistants were referred by the nurse managers and I went to the unit to speak personally with the potential participants for recruitment and to assess inclusion criteria. Nurse 3 and Nurse 4 gave me the names of the physicians who were involved in their experiences but I was unable to secure an interview with them after repeated attempts phone calls and messages. These physicians were in private practice and stated they were very busy. I believe my success in securing interviews with the other physicians was because they were in a teaching hospital environment where research participation is expected and encouraged. On December 15, 2008 my position at the hospital was eliminated and access to future participants was limited and data collection efforts ceased. This study has a total of 10 participants who cared for six dying patients in a medical surgical unit.

Signed informed consent was obtained prior to the commencement of all interviews. The participants were informed of the right to withdraw from the study at any time, for any reason. Confidentiality was maintained through the use of pseudonyms. HIPAA guidelines were
followed to protect confidential medical information of patients and any identifying data was deleted in the typed transcripts.

**Level Two: Telling About Experience**

All interviews were conducted by me to “provoke story telling” which allowed the participants tell the narratives about their experiences (Riessman, 2002; Czarniawska, 2004). The semi-structured interviews took place in varied locations at a mutually agreeable time. Nurse 1 was in her home, the rest of the interviews were in conference rooms at the hospital or adjourning offices. The areas selected were quiet and private so that the participant could speak freely and the recording would be audible during transcription. The interview guide was utilized to guide questioning so that the research questions would be addressed but the aim of each interview was to transform the participant – researcher “relationship into one of narrator and listener” (Chase, 2005, p. 660). Communication techniques such as open ended question, rephrasing and asking for clarification by me facilitated the participant to elaborate or tell their story not merely answer a set of predetermined questions.

Each interview was audio recorded after the consent was signed. Field notes and observations were recorded during and immediately after each interview. I listened to the recordings immediately after the interview to check for audibility and completeness. The audio recordings and field notes were examined for ambiguous or unclear sections and to identify a general plot or theme of the narrative, any thoughts or observances by the researcher were also notated in the field notes.

The consents and pseudonym code key were placed in a locked file cabinet and the audio recordings, transcripts, computer files were password protected in the researcher’s home office. Only the researcher had access to confidential information. Upon completion of this dissertation
and successful defense, the code key, audio tapes and any identifying information will be destroyed or shredded.

Patton (2002) states, “The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observation/analytical capabilities of the researcher than sample size” (p. 245). Table 1 is a detailed summary of the participants’ participation.

Table 3-1. Interview statistics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Recorded Minutes</th>
<th>Total Words</th>
<th>Participant’s Words</th>
<th>Transcript%</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>N1</td>
<td>52:49:00</td>
<td>6107.0</td>
<td>5452.0</td>
</tr>
<tr>
<td>#2</td>
<td>N2</td>
<td>48:52:00</td>
<td>8817.0</td>
<td>8294.0</td>
</tr>
<tr>
<td>#3</td>
<td>N3</td>
<td>47:30:00</td>
<td>6281.0</td>
<td>5238.0</td>
</tr>
<tr>
<td>#4</td>
<td>N4</td>
<td>31:07:00</td>
<td>3545.0</td>
<td>2389.0</td>
</tr>
<tr>
<td>#5</td>
<td>NA1</td>
<td>33:13:00</td>
<td>3794.0</td>
<td>2067.0</td>
</tr>
<tr>
<td>#6</td>
<td>NA2</td>
<td>56:46:00</td>
<td>7277.0</td>
<td>6436.0</td>
</tr>
<tr>
<td>#7</td>
<td>NA3</td>
<td>42:00:00</td>
<td>6458.0</td>
<td>5742.0</td>
</tr>
<tr>
<td>#8</td>
<td>P1</td>
<td>54:41:00</td>
<td>8878.0</td>
<td>7746.0</td>
</tr>
<tr>
<td>#9</td>
<td>P2</td>
<td>54:33:00</td>
<td>8779.0</td>
<td>8076.0</td>
</tr>
<tr>
<td>#10</td>
<td>P3</td>
<td>52:34:00</td>
<td>5921.0</td>
<td>4168.0</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>474:05:00</td>
<td>65857.0</td>
<td>55608.0</td>
</tr>
<tr>
<td>Average</td>
<td></td>
<td>47:24:30</td>
<td>6585.7</td>
<td>5560.8</td>
</tr>
<tr>
<td>Total Hours</td>
<td></td>
<td>7:54:05</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The ten participants are included in this study generated a total of 474:05 minutes of audio tape time. Each recorded interview averaged 47:25 minutes. I found the participants willing to speak at length about their experiences with little prompting from me; their words averaged 81.6% of the recording/transcript. Six participants spoke more than 85% of the transcript. I felt at times during the interviews as they spewed words, it was akin to uncorking a bottle of champagne; words flowed. Since each participant told their story without much prodding by the researcher it authenticates the richness of the data and the validity that these stories are the participants’ stories and not that of the researcher.
Level Three: Transcribing Experience

Riessman (2002) states, “Transcribing, the third level of representation…is incomplete, partial and selective” (p. 224). It is impossible to capture the entire conversation (Riessman, 2002). An audio recording only discloses the sounds of communication and does not capture the nonverbal. I listened to the audio recording several times and then transcribed the interviews verbatim, (taking out identifying information) utilizing Microsoft Word software. The manner in which the transcription is typed to illustrate pauses by four periods (…..) and emotions by using capital letters (EMOTION) is the beginning of interpretation and analysis.

Transcribing is also the first step in “Interpreting the Stories” or “what do they say?” Notes were also made during the listening and transcribing of the audiotape. (See Appendix B for Sample Complete Transcript with Notes). Since data management is the first loop of the data analysis spiral; the data was organized by computer file headings in Microsoft Word documents that were password protected and paper file folders, labeled with the pseudonym (Creswell, 1998). The transcriptions, notes and field notes were compared with the recorded interviews to ensure accuracy and clarity by the researcher/interviewer and additional notations were made on the transcripts about voice inflections or other verbal and non-verbal communications observed (Riessman, 2002). Common themes, new or emergent topics were noted that might be appropriate to address in subsequent interviews.

Level Four: Analyzing Experience

The fourth level of representation comes forth as the transcripts are analyzed. It was necessary to confirm that each participant had experienced a meaningful experience when caring for a dying patient to achieve Riessman’s first level or “Attending to Experience” before analysis of their story was continued (2002). Each participant readily expressed that the experience was indeed meaningful to them; the participants remembered many details of the deaths and their
emotions and as evidenced by the tears and nervous laughter during the telling of their stories as they continued to grapple with the experiences. For some of the participants, it was a recent event, others it was over a year. They reflected on their actions and made observations of others as they told their stories to me. Once Level One was re-verified for meaning, the narrative analysis was continued.

The structure of each verbatim transcript was examined for “how do they say it” and notes were made for reference (Czarniawska, 2004). The transcripts were arranged and re-arranged to provide insight and shape the narrative with these questions considered (Riessman, 2002)

- How is it organized?
- Why does an informant develop the tale this way in conversation with this listener?

The transcript was examined for underlying propositions and unspoken assumptions that “make the talk sensible, including what is taken for granted by the speaker and listener” (Riessman, 2002, p. 255-6). The transcripts were shared with other doctoral students and/or experienced qualitative researchers to compare interpretations of the narrative and identify any missed plots or themes.

The narratives were then deconstructed by removing any irrelevant clauses and lines to parse down to the skeleton plot. Data reduction of extraneous clauses continued until the core narrative was obtained. Then the story was reconstructed into a new narrative. The researcher’s interpretations were written into a new narrative in draft form which was circulated among other qualitative researchers (committee members and peer doctoral students) for comments and their interpretations of the narrative. Each participant’s story was cataloged in this manner to insure that the stories had not been parsed too extremely or that the story was still evident. Then each narrative was returned to numbered line formats and separated into “stanzas” for meaningful interpretation using Riessman’s method of Poetic Analysis (2002). Careful thought was given to
interpretation (See Appendix C). A new narrative summary was then written for each participant’s story (See Appendix D and E).

After all of the stories were collected and analyzed with participants who cared for the same patient, their stories were compared. As a next step, nurses’ stories were compared with other nurses, physicians with other physicians, nursing assistants with other assistants. Finally, stories and plots of all of the narratives (nurses, physicians and nursing assistants) were compared and interpreted for meaning by the researcher. Drafts were circulated to other qualitative researchers for their comments. These comments were incorporated into the final version or new narrative. The presentation of the data consists of this written dissertation and a condensed format for publication in professional peer-reviewed journals will be developed. This is the fifth and final level of representation; the reader will interpret what is written (Riessman, 2002).

Application of Narrative Analysis to the Proposed Study

Patton (2002) states, “The quality of the information obtained during an interview is largely dependent on the interviewer” (p. 341). To promote rigor and to develop skill, I conducted two practice interviews, transcriptions and analysis of the narrative. This practice enabled me to learn “to pay attention, see what there is to see, and hear what there is to hear” (p. 260). Each practice interview and analysis were critiqued by another researcher or doctoral student to improve my skill in the method, as I realize that I am the instrument for the data collection and my interpretations are based upon my own experiences caring for the dying. I am cognizant of these limitations and strived to overcome any deficiencies.

Rigorous data collection techniques were employed with the aid of an interview guide to provide topics and systematic interviewing (Patton, 2002). Interviews were scheduled for two hours in length to allow ample time for the participant to tell their story. Immediately after the
interview, the audio recording was checked for functionality and the interview notes were reviewed for clarity. Questions that arose were clarified by the participant to ensure understanding.

The researcher used verification of accuracy by comparing subjects’ experiences and capturing the similarities and outliers. The study was guided by experienced qualitative researchers and members of my dissertation committee. Samples of the data analysis were reviewed with Nurse 1 to solicit feedback to validate the experiences and meaning. She agreed that I had captured her story accurately and reading it brought back the feelings and emotions she had experienced during that experience.

**Reliability and Validity**

Reliability and validity are not effective evaluation tools of narrative analysis (Riessman, 2002). Polkinghorne (1988) refers to reliability as “the dependability of the data” or that the field notes and transcripts are accurate (p. 176). The narrative can change with each telling. Narratives of the same event can be constructed in a different manner by the narrator or the listener or reader because it is a selective process. Riessman (2002) states, “There is no reason to assume that an individual’s narrative will, or should be, entirely consistent from one setting to the next” (p.257).

Validity in the narrative study is the “strength of the analysis of data (Polkinghorne, 1988, p. 176). Validation or trustworthiness in narrative analysis can be approached in at least four ways (Riessman, 2002). Persuasiveness is the first criteria of validation of the interpretation, is it believable? In this study great care was taken to preserve the participant’s story, content and emotions in the reconstruction of the narratives. Riessman (2002, p. 258) states that persuasiveness is “greatest when the theoretical claims are supported with evidence from the informants’ accounts and when alternative interpretations of the data are considered”. In Chapter
5 (Discussion), the study findings are discussed in detail as it relates to the current theories and other end of life research.

Correspondence is the second criteria. It involves taking the results back to the participants for verification. This was done only with Nurse 1 because of limited access to the participants over the period of time. She verified the accuracy of the interpretations and transcripts but other participant verification would strengthen satisfaction of this criteria.

Coherence is the third criteria for validation of narratives. Riessman (2002) speaks about three types of coherence, global, local and thermal. Global coherence insures that the narrative is consistent in overall goals and beliefs of the speaker. The narrators’ goals in this study were to describe how it felt to care for a dying patient and if the experience matched their personal beliefs of how they thought it should be. Local coherence is whether there are recurrent themes that bring the text together. An example of local coherence in a narrative of this study was when Nurse 2 talked about how her patient died alone; she thought it was not right for a person to be alone when they died. Nurse 2 continually talked about her feelings about this throughout her narrative. Thermal coherence is about the content of the narrative in which sections focus on themes that are important and frequent. Nurse 4 repeatedly said that she did not want the patient to die on her shift because she was unsure of what to do. Nurse 2 did not want her patient to die alone. Physician 3 wanted to give the patient’s family hope so that he could develop rapport and help them accept that the patient was dying.

The last criterion is pragmatic use or “can the knowledge be validated and used within the scientific community?” This criterion was accomplished in this study by adhering to the rigorous method outlined in this chapter. In the appendix there are samples of the transcripts, poetic structure analysis and preliminary narrative analysis reports.
Limitations

Narrative analysis is not useful when large numbers of faceless subjects are studied (Riessman, 2002). Since the participants and I were employed at the same institution, I was familiar with them and their environment. This method is slow and meticulous and requires attention to subtlety. Narratives can change and can be influenced by the participant’s life events, audience and time. The resulting interpretation is only a snapshot in time.

Another limitation is that this study was conducted by a doctoral student who was learning the method during the study. Time was also an issue; narrative analysis is lengthy and complex. There were volumes of pages to interpret and analyze. Decisions were made as to what is important in this study and answer the research questions, which may limit the richness of the study. Every effort was made to be thorough during the analysis, and guidance was sought from other researchers throughout the process.

Summary

This qualitative research study was conducted in the interpretive philosophical tradition. The ontological assumption of this type of qualitative research is that reality is subjective and is as perceived by the participant (Creswell, 1994). This study explores the experiences of healthcare providers (participants) caring for dying patients from their own personal story or narrative. The epistemological assumption is that the researcher interacts with the participant to gather data with semi-structured interviews.

The interviews (10) were conducted in the field (the hospital) or an environment (conference room or participant’s home) in which the participants were comfortable (Jacox et al., 1999). Interpretations of the participants’ experiences in this study were made using the method of narrative analysis based upon narrative theory. Czarniawska’s description of the flow of narrative analysis from field of practice to the field of research guided me in conceptualizing
how to bring an event to research (2004). Riessman’s five levels of interpretation and poetic structure analysis provided the structure and theoretical framework for the method of narrative analysis utilized (2002). The participant’s stories were transcribed, analyzed and interpreted by the researcher using field notes, observations and re-transcription of the transcripts. The core plot or story of each participant was identified. Analysis of the narrative included how it is structured and why it is being told, unnecessary or irrelevant information was eliminated to parse the story to its core. The narrative was again re-transcribed into stanzas for poetic structure analysis to reveal themes entwined within. A new story or narrative was written by the researcher in Chapter 4 (Findings), which was then compared against other participant’s rewritten stories to capture the interpretations to answer the research questions of this study. The process of narrative analysis is completed in the narrative that the researcher publishes or in essence, this dissertation.
CHAPTER 4
FINDINGS

Introduction

In this chapter the findings from the narrative analysis of each participant’s story is presented as Level 4 (Analyzing) of Riessman’s Levels of Representation in the Research Process. Riessman (2002) believes that at each level there is interpretation and text created because the text is a symbol of the primary experience. The “meaning is ambiguous because it arises out of the process of interaction between people: self, teller, listener and recorder, analyst and reader” (Riessman, 2002, p. 228). Application of Riessman’s method facilitates immersion into the data, but also examination and thoughtfulness at the different levels; the narratives created by me are only partial reality because “meaning is fluid and contextual, not fixed and universal” (p. 228). It is with that premise that these findings are presented in this chapter. Each of the three research questions are addressed in separate sections and then all of the findings are summarized at the end of this chapter. The next section of this chapter addresses the first research question: What are the experiences of healthcare providers (physicians, nurses and nursing assistants) when caring for a patient in the last 24 hours of life?

The Experiences –Research Question #1

This research question is addressed by the participants telling their personal stories about the experience of caring for a patient in the last 24 hours of life. The narratives describing the participants’ experiences are grouped into sections by the six patients (Patient A – Patient F) who died, beginning with Patient A. The same nurse cared for Patient A and Patient B.

Patient A

Patient A was a Jewish elderly man who had been admitted the night before his death with respiratory distress/failure to the medical unit of a teaching facility. He had been alert and
oriented prior to this present illness, although he had progressively been showing signs of weakening in the previous weeks. It was believed he acquired pneumonia from aspiration. Palliative care and hospice had been consulted, but the family did not agree to the palliative treatment plan, instead requesting that aggressive care be continued even though a “Do Not Resuscitate” order was in place at the request of the patient from previous admissions. This researcher was also the nurse on the Palliative Care Team during this time and is a participant observer of this case study. Nurse 2 (N2), Physician 3 (P3) and Nursing Assistant 1 (NA1) shared in the care of this patient and his death. The interviews with Nurse 2, Physician 3 and Nursing Assistant 1 were conducted approximately two years after the death of Patient A.

**Nurse 2**

This participant identified as (N2) is 30 years old, white, a Catholic woman and had less than six months experience as a RN when Patient A died. She had worked in hospitals previously as a nursing assistant and unit secretary while she attended a community college for her nursing degree. She was assigned five patients and had heard in report that two of her patients were terminal, but it was another patient who was expected to die that day, not Patient A.

I had been told that he was terminal, that (death) was expected, but not any time soon or anything. She (another patient dying) was the room was right next to him. It was the one we thought that would go pretty quickly, and I think she hung on for a couple of days. So it was kind of like Okay, THIS is not a GOOD Day! [laugh]

She began her day with much trepidation because she had never had a patient die on her shift. She was “very scared” and “hesitant” about what the day would bring. After N2 did her initial rounds on her patients, she realized that the report she had received did not match her assessment of Patient A’s condition.

I’m thinking to myself, did I get the right report? Is this the right person? You know ‘cause from what I understood and everything I was looking at was there was nothing that could be done for this patient.
A palliative care consult had been ordered, but because “this doctor’s like you know, reassuring the family there are other steps we can do,” she felt a sense of dissonance. She did not understand why Physician 3 (P3) suggested the tests because “it was kind of like, but what are we going to do with those results? Is it going to change the end?”

The palliative care physician and nurse (this researcher) met with the family later that morning after examining the patient and speaking with N2. A palliative care approach was suggested because the palliative care team felt that Patient A was actively dying; the family agreed to meet with hospice. N2 was concerned that her patient might die. “And I just remember I kept going into that patient, from everything you learn in school you could tell that he wasn’t doing well. He was not responsive at all.” P3 spoke with the family after the palliative care consult and N2 felt that “they were kind of unsure which way to go”.

The family had wanted to talk with palliative care and hospice but then again once we’d get going with that, then it’s like well the doctor said we can do this in the morning so. And the doctor wound up reassuring them we can do this in the morning, we can do more tests. And take it from there. And the family had left.

N2 was not aware that P3 had canceled the tests later, after consulting with his supervisor and that he had notified the family. She thought that maybe palliative care had been wrong because the family had felt comfortable to leave, stating they would return in the next day. When Patient A began to have some cardiac arrhythmias later that morning, N2 was busy with the other patient who was expected to die that day and did not place the call to the physician or administer the medication he ordered, her team leader performed these tasks and the patient seemed to stabilize. Shortly after that, NA1 told N2 that Patient A was “gone”. It was a surprise to her because she thought he was doing better after he had received the medication and because after the medical team had not followed the palliative care plan, instead opting for aggressive treatment measures, N2 had ignored her feelings that Patient A was dying.
I’ve always heard it can be quick or it can go on for days when you think it’s going to be quick, you never know. It was just kind of like a shock like, he’s gone, it was like the first thought was [laugh] WHERE? But then I realized, Oh, my God. It was just like Wow!

When she realized that he had died alone without anyone present, N2 became upset and remembered “feeling so bad that I wasn’t in the room and I was thinking, ‘Oh my gosh, this man died alone.’” Although N2’s belief system and spirituality provided her some comfort that “spirits and family” welcomed Patient A to heaven, she regretted not being with him when he died.

And I think that is why I was kind of upset when I wasn’t there, cause I was like, Oh, my God, he was there all alone. Even though I’m sure he wasn’t alone, there were spirits and family members’ things like that out there, but as far as a human being just to sit there and hold his hand. Just to say it’s OK. That kind of, that upset me more.

N2 thought that the sudden death had also surprised the doctor and described how she felt he had a hard time telling the family by telephone. It frustrated her that he told the family the patient “had taken a turn for the worse” and seemed to have difficulty saying the words that he had died.

The doctor was quite shocked when he found out too. I don’t think he believed it, what happened so suddenly either. When the doctor did make the call to tell the family, the doctor on the phone said, “Your father has taken a turn for the worse.” And my whole thing was, he’s taken a turn for the worse? HE DIED! And then he said, Well, I’ll just come out and say it, he died. And I mean, he, the doctor I think was shocked too because he didn’t expect it.

She speculated in the interview two years later that it was P3’s own lack of experience or feelings of failure that guided his actions and why he seemed unable to recognize that Patient A was dying. She thought it was important to him to appear to the family that they were not giving up.

Either one, the inexperience with death with maybe…. he had….or …. I don’t want to be a failure; I want to cure this person. I want to give you hope, because I don’t want him to go. You know, then again, I don’t know, I’m just going on what I feel.
N2 stated that “people have a hard time, especially doctors accepting when a patient is dying.” She believes it is “hard to tell the family” and “we don’t want to say there is nothing else to do.” Patient A’s death was a learning experience for both of them because “he was a new resident, I (N2) was a new nurse.” This inexperience contributed to N2’s lack of confidence in her own assessment. She felt guilty that she had not talked with the family about what she believed was happening; instead she supported P3’s plan of care.

I feel like I let the family… down because they came to me at one point and said, you know, we have palliative care telling us this and we have the doctors saying this and they felt it was one group saying Ok look, we show you signs, these are things that happen when somebody is dying. And then you have another side of it saying we can do these tests in the morning and they were like, what’s your take on it?…. I feel like there were different sides telling different people different things.

N2’s inability to voice her opinion to the family suggests that she did not have confidence in her own assessment and did not feel that there was a clear plan of care to guide her. She felt that the family had been misinformed and was afraid they hadn’t had an opportunity to say goodbye.

N2’s story suggests that she needed to have closure with her patient so she participated in the post mortem care. The special care she gave her patient after death was to compensate for her absence at the time of death. She prayed over the body, a ritual that she continues today when she hears about a death.

And so I went into the room and the PCT [Patient Care Tech or Nursing Assistant 1] who was working with me was in there, she said, “You know I got it all, I’ll remove everything and clean him up,” and I said, no, I really want to be here, it’s my first patient who died on me, with me. She said, “Oh OK” and she just told me what she was doing.

N2’s use of words “my first patient who died on me” suggests that she took Patient A’s death personally and implies her feelings of guilt for not being present at his death. She further
personalized it and applied her belief system when she prayed to her dead father to welcome him
to heaven.

I remember just taking his hand and saying the “Our Father” to myself (laugh) and
just said Dad please be up there with him and show him around.

N2 remembers being “sad” that Patient A had died alone but found solace in her own
beliefs that death is also “a new birth” and it was comforting to think that her own father
welcomed Patient A to heaven. She developed a ritual of praying to her father “whenever I know
of somebody who has passed away or a patient of mine”.

She talked about visions of the afterlife, that there were two possibilities, it was either
“dark or gloomy” or a beautiful place where “you walk with all of the fog rolling and the gates
open up and there is this beautiful cherry tree”. She doesn’t want someone to die alone because
they may be fearful without someone holding their hand. She hoped that Patient A had some
family to greet him after death and wasn’t floating “around in this dark space alone again
forever, and ever and ever”, a thought that scared “the heck out of” her.

N2 described her feelings the rest of that day as stunned. She said the other nurses were
supportive because they said they remembered how they felt with their first patient’s death.
During the interview she was frequently tearful as she articulated her memory of her feelings,
shock and tears. The experience made her evaluate whether she had chosen the right profession
because she couldn’t forget it.

Honestly it made me think, ‘Is this, what I want to do?’ You know this is part of
nursing, this is part of life and after I left work that day I drove straight to my
mother’s house and my mother has been a nurse for a long time and she’s always
been my mentor, my sounding block and I told her about it and I said, God, I just
can’t stop thinking about it.
Her mother, an experienced oncology nurse, suggested that N2 was suffering from “post traumatic stress syndrome” because she was having difficulty dealing with her memories of the death. She described how she had difficulty sleeping for a week after Patient A died.

Every time I would shut my eyes to go to sleep, I would just replay going into his room and seeing him there. Or just little parts of it. This was a man who I had never met before. I had known him a couple of hours…. that was it. And it still just, the experience touched me and I can still remember it, I can still remember what it felt like going into that room and seeing him. And being a part of washing him up and taking care of him…. it’s something I don’t think I’ll ever forget.

N2 found the whole experience to be “very hard” and she describes how she dealt with the “thoughts running through” her mind made her “a quiet person for a while”. She reflected how the experience was different from her father’s death.

It was different than my father, my father I knew, I expected, I was involved in the whole entire process, but this is someone who’s here in the morning and you’re taking care of him and then you get close to him in the small amount of time and what’s going on with him. It was definitely a new experience.

This experience has changed Nurse 2. It made her reflect her choice of profession and she realized that she had been “scared” to go into the room and find a dead patient. She said that if she could have changed anything, she wished that she had been present at his death. But she acknowledges that the experience, although traumatic, has made her a better nurse. She realizes her role as a patient advocate is important and “it kind of gave me a little bit more…. drive to stand up a little bit more, instead of just saying, you’re the doctor.” She has a goal for her patients, “I want to make sure that they have the best they can…. the best life, the best death, the best whatever.”

**Physician 3**

This participant identified as (P3) was also a new practitioner; Patient A was “probably one of the first” patients that P3 had cared for that died during his first month of his Family Practice residency, over two years prior to the interview. P3 is in his early 30’s, Catholic
and Hispanic. Spanish is his native language and he spoke with a heavy accent and at times he was difficult to understand to transcribe his words from the audio recording. He has lived in Northeast Florida for the past two and one-half years. He plans to specialize in sports medicine, a specialty where he will not usually care for older and critically ill or dying patients. P3 stated, “I remember that patient; he had pneumonia and died shortly after arriving to the hospital and getting to palliative care consult.” P3 remembered that family had agreed to a palliative care plan during the palliative care conference and a consult for hospice had been called. P3 spoke about the son who had the power of attorney and questioned the credibility of the Palliative Care consultant’s opinion because the consultant indicated the patient’s report of “angels” was an illustration or sign that death was imminent and that the patient knew it.

In that specific case I remember one of the attending that did the consultation for Palliative Medicine said that he (the patient) was seeing angels in the ceiling…. and that was when he (the son) blocked out and said, ‘I don’t want to talk about it, this with this guy anymore.’ It was a specific phrase, so that’s when he turns to me.

P3 felt that the family turned to him because they were not prepared to accept impending death because the patient had been alert the day before admission and they wanted to believe that the pneumonia was reversible. He thought that by offering them hope and further diagnostic testing, he could help prepare the son to accept palliative care by providing additional diagnostic data or hard medical science, not intangible “angels”.

I mean to that…. He was not prepared. I think that is all about being prepared and knowing where you are going. And… when you have a weak heart, you have pneumonia; everything exacerbates and sometimes the heart just can’t compensate for what’s going on. It’s just, he was talking yesterday, now he’s all confused and he wanted to make sure that we’re not…. that palliative care was not just letting him die.

P3 felt that the family did not believe that palliative care was the correct approach and he wanted to support the family to allow them (the son) time to accept the prognosis. P3 suggested
additional tests and treatments to give the family reassurance that “everything that could be done to help was done”.

I felt the urge to talk to the family members about what was going on. And giving reassurance, that what we were doing was the right thing to do. So I had to invest a lot of time with the family member, explaining what was going on. He (the son) had some requests and I tried to help, you know with that as much as I could.

He felt comfortable “and I think he (the son) was…. comfortable with me because I was trying to help him.” P3 thought the son “felt that I was trying to do more than other people and that’s why he felt more comfortable with me.” P3 believed that he was preparing the family by giving time to process the prognosis by not withdrawing any treatment and suggesting further tests so he could gather empiric evidence that Patient A’s prognosis was poor. He felt it gave them hope that the patient would recover by suggesting that he may respond to the treatments in time.

I probably made…. gave him a little bit of hope saying, ‘Well maybe seeing if the antibiotics kick in and we do this, or we get a V-Q [pulmonary ventilation/perfusion] scan…. Maybe it’s a PE [pulmonary embolus] or something.’ Maybe that is what he was looking for hope, more than just comfort. And I was giving him a little bit more that that the family in that case, the power of attorney, thought that should be done.

The physician felt that it was permissible to follow the aggressive plan of care because “we don’t withdraw treatment if they are not causing any discomfort.” He thought the family had considered “withdrawing antibiotics and letting him die peacefully” but was not ready to accept that this was the end.

So…. if that’s what he thought and that’s something I could do and I agree then and if it’s moral, I think I would do the same thing. That’s what he wanted to do with informed consent and I think it was…. I did whatever was, I should do. Withdrawal of treatment is not necessarily something you need to do. I mean you can continue the antibiotics and you should continue at plan.
P3 learned from the radiologist later that morning that the benefits from the scan he ordered “would actually do more harm if done with the contrast” and the patient’s “renal failure” would worsen.

But it would not be done. I talked with the radiologist and he said that the benefits for the tests and the information that we were going to get were not going to be important in any decision making.

He now regrets suggesting the scan to the family and realizes that at the time he did not have enough experience to know that it would not be beneficial.

I shouldn’t have pushed for any other test, but definitely the treatment, the other part was done, I wouldn’t change it and in that case I didn’t have enough experience. And now with more experience, I agree with the radiologist and doing x or y tests will not help him in his illness at this point or it’s not going to be any benefit.

He found himself in an uncomfortable position to have to go back to the family and tell them that there would be no more testing.

I shouldn’t have said that to the family member so now they are all pumped up that I am going to do a CT scan and…. now I have to tell them that it’s not a good idea and so…. and that’s not a very comfortable…. But I did tell them.

P3 speculated that he should have been more direct with the family about the patient’s condition. He does feel that he did provide good care to the patient and family, but did not have enough time to prepare the son for the death because the son “was searching for hope”. P3 felt that if there had been more time to tell “him that he is not getting better, that then things are trending down to worse; it could have actually made him more aware of what was really going to pass away soon.

I didn’t have enough time for that to happen…. So, but maybe the next day, I could tell him, the kidney’s not working as well as yesterday, so you know his breathing is not doing well and is getting worse. Maybe that could have happened. That little more time could have changed something with the family member, but that is just a speculation.
Even though P3 felt that he had not prepared the family for Patient A’s death, he felt he had provided good care.

Well as long as I know that I did what I needed to do and that the patient got what he or at least what the power of attorney wanted, I feel that I have fulfilled my mission there.

The death of a patient causes P3 to feel “sad” and affects him the rest of the day but the job requires him to continue to work caring for his other patients.

Yeah, it impacts my day. How do I feel? That…. I don’t know what to feel, it’s sad but you have to continue working because there are other things…. I…. it doesn’t affect me on my…. on the way I work with other patients.

He deals with his feelings later by processing his thoughts while running or finding support from his friends. He does not feel that a patient’s death is “a failure” as long as he is comfortable in the care he provided.

Sometimes I might just go out running and think about it a little bit and think about other things. I could talk to friends and tell them what happened. As long as I know that I did what I needed to do when I feel comfortable, I feel comfortable. So it’s sad, but…. Could be a little sad, but I don’t feel frustrated or anything like that.

P3 believes the experience of caring for Patient A is one that he will continue to remember and the good rapport he had when dealing with his family. He acknowledges that this was a learning experience and this and other patients will guide him by providing a reference point in the future to help him be a better physician.

I still remember after the two years the day the patient…. I remember a lot of other patient that have not died, but had some crucial decision making points and those things stick with you for the rest of your life, cause it is going to happen again sometime and you will have that as a reference.

Nursing Assistant 1

This participant, identified as NA1, is an African-American woman in her 30’s who views her job as a nursing assistant as a means to meet her “responsibilities”. She considered a career as a RN but after completing the prerequisites for nursing school has decided not to continue her
studies in nursing; she has changed her major to computers. She feels her personality is not “forceful” because she keeps to herself and does not try to impose her will on others. She realized that as a nurse she “would have to work with the person to get them to comply” and does not feel she can do that. It is important to her to have defined tasks and structure in her role.

NA1 remembered Patient A; it was the third death that she had experienced as a nursing assistant and that the death of Patient A did not affect her, citing that she had “a different take on death and dying” and that “living is dying”. She spoke about the family conflict and denial that Patient A was dying.

We have some family members and they think that their parents are going to live forever and we know that we are not going to live forever, but we be in denial.

She felt that “the other siblings understood” that Patient A was dying but it was the son who “was like never there or didn’t do anything…. that was not accepting of the situation and was trying to take control”. NA1 did not get “caught up” into the family dynamics but questioned why the family would want to keep someone alive to suffer.

I was just saying to myself, I don’t know how you really feel or what you have done to your parent but if you love them so much why do you want them to stay here to suffer? No, I’m just say, ‘cause personally I wouldn’t.

NA1 has observed with other patients the sadness and feelings of neglect when they are admitted from nursing homes.

Because like some family members they’d be like, oh, let’s do this and let’s do that and then that family member wind up coming back how are you and your family members getting along? Oh, they put me in a nursing home. It’s like I should have stayed as a DNR cause at the time it sounds great.

These patient’s negative experiences and feelings about nursing homes has shaped NA1’s desire to help preserve a person’s dignity and to prevent suffering by making sure that her patients are well cared for and comfortable. She has given instructions to her family that she would not want her life prolonged if she would not most likely recover because she feels that
there would be “no quality of life” if she was a “vegetable” and she would “have to depend on someone else to do anything.” NA1 focuses on the patient’s care and remains in the shadows, out of sight to the physicians when they come in to see the patient.

I just deal with the patient. ‘I just don’t say anything. Cause I don’t want to get caught up into everything. When the doctors come, I leave. I give them their privacy.

She feels that she spends more time with the patient than the nurses and does not say anything to the nurses because she does not want conflict.

Well I guess we are closer to them, ‘cause we go into the room with them and they’re conversate with us because over half of the nurses don’t want to be bothered with them and I just leave it alone. I just deal with the patient. I just don’t say anything. ‘Cause I don’t want to get caught up into everything.

NA1 was surprised at N2’s caring and emotional reaction to the patient’s death because in her experience most nurses were not interested in hands-on care after a patient had died. It seemed to cause some role confusion for her when N2 insisted on providing the post mortem care (the nurse usually handles the paperwork and deals with the family, not the physical post mortem care).

She care. Well, I was… this sounds mean but Oh God, come on N2 you are in the medical field, people die every day. I know that sounds mean. I didn’t say anything to her though. She wanted to be hands on all the way to the end. It was surprising! So I’m like oh well they died, OK. Is anybody gonna come see the body? But she was definitely there. Tagging and bagging and taking him to the morgue.

NA1 seemed to have a very clear definition of her job; she met the needs of her patients. It could be speculated that her inability to confront or reluctance “to get caught up into everything” is actually be the reason she was pursuing a career in computer repair because she can do her tasks on a computer without emotional events. “I’m guess I’m used to the get in and get out. That’s just the way I have always been.”
**Analysis of Patient A’s death narrative**

This death illustrates the disharmony that can occur at end of life when family members and/or staff cannot talk openly about death. This phenomenon has been likened to the metaphor of an elephant in the room that everybody sees, but ignores its existence and they do not talk about it. This type of denial of impending death caused intense suffering of the nurse after the patient died alone. This is an example of how societal influences of denying death as a natural process can influence family decision making and the acceptance of impending death when the family (son) asked the physician to perform additional tests refusing to believe that the patient was dying.

The inexperienced nurse was troubled by the incongruence of what she thought versus the dialogue between the family and physician. She sensed that the patient was dying and believed that the palliative care plan was correct, but the inexperienced physician offered the family aggressive testing, creating feelings of hope that the palliative care team was wrong or creating an ethical dilemma for the young nurse. The nurse did not feel comfortable in talking about her feelings with the family because she lacked confidence in her assessment due to inexperience. She and the family distanced themselves by not discussing the impending death and avoiding spending time with the patient. When the patient died later that day, the nurse became very upset because she felt she had not fulfilled her duty to help prepare the patient, family and even herself for the death. She was distressed that physician did not help prepare the family or her for the death because he did not support palliative care’s prognosis, he spoke of additional testing and canceled the hospice consult. She was not aware of the physician’s intent to over time help the family accept the impending death. Her actions of assisting in the postmortem care and development of prayer rituals to her deceased father were attempts to provide her own comfort and absolve the guilt she felt for not being present when her patient died. This patient’s death
was very stressful to the nurse as evidenced by the fact that she felt guilty and dwelled on it, actually questioning whether she had chosen the correct profession.

The physician felt that the son, who had the power of attorney, needed more time to accept his father’s prognosis and wanted to instill hope that Patient A might recover by offering to do further testing and continue aggressive care. He felt that this was necessary to build rapport and trust with the son because the son doubted the creditability of the palliative care consultant’s opinion of impending death. The son did not accept the statement by the palliative care team that the patient reporting seeing “angels in the ceiling” as a sign of impending death; he believed that the patient was confused and did not believe that the patient was dying. The physician’s own inexperience contributed to his suggestion of a test that was not indicated in his attempts to instill hope for the son and he found it to be very uncomfortable to have to later tell the family the test would not be done. Two years after the death and more experienced as a physician, he pondered whether he should have been more direct with the family in the beginning because the patient died that day. He felt he did not have time to prepare them because the patient died so quickly. He feels now with more experience he is able to recognize the signs of impending death, but he feels he gave the family and the patient good care.

The nursing assistant overheard the conversation that the physician had with the family after the palliative care conference and she thought that the patient was suffering and that the family was in denial. She agreed with the palliative care team that he was dying although she did not discuss her feelings with the nurse or the family, preferring not to become involved. The nursing assistant told the nurse that the patient had died alone and she began the postmortem care of cleaning up the body. The nurse’s tears and emotional reaction to the death exasperated her because she thought a nurse should accept death because she was “in the medical field and
people die every day.” It surprised her that the nurse insisted that she participate because usually only nursing assistants perform postmortem care. She felt that the patient was in a better place and his death did not bother her, citing that she hadn’t thought about it since that day.

Patient A’s death impacted each healthcare provider differently. The physician used it as a learning experience, but did not describe any distress other than his discomfort when he had to tell the family he had been wrong to suggest the test. The nursing assistant distanced herself from the feelings and felt that the death was not a bad thing. She felt the family had been in denial and that the nurse’s emotions were inappropriate for a person in the medical field. The experience for the nurse was very painful as evidenced by her tears and reference to the death causing her post traumatic stress. She had had an opportunity to examine her feelings in the two years since the death and found the experience to be quite different with Patient B (described in the next section) where his impending death was spoken about openly amongst the healthcare providers and family.

**Patient B**

Patient B was a white male in his 50’s when Nurse 2 (N2) and Physician 1 (P1) shared in his care during the last hours of life. He was married and his wife was present at his bedside and actively participating in his care, as she had during his long illness and hospitalizations. She provided direction to the medical team the care she wanted for her husband. N2 had been told in report prior to meeting the wife that she had been upset with the care that Patient B had received and that she blamed healthcare providers for his present state of illness. The patient was transferred to the medical floor from intensive care to die and he was actively dying when N2 became his nurse.
Nurse 2

The appointment for this interview was made with Nurse 2 (N2) to talk about Patient A, but when she came to my office that afternoon she appeared to be very excited. She told me she had taken care of a patient the previous evening that had died and she wanted to talk about her experience with him. N2 began the narrative in a very factual manner, almost as if reciting a case study of a patient for a teacher. She described the patient’s condition in detail and what had transpired over the past few days as he declined. Her initial assessment validated the report she had received that he was indeed dying and in very poor condition.

Basically he was, when he came up to me, breathing just very labored, uneven, his respirations were about 10 a minute. He was on 50 mics of fentanyl (pain medication) an hour. He was doing a little bit of moaning and that was extremely jaundiced and bloated everywhere. I have never seen 4+ pitting edema before. But on him it was just unbelievable!

N2 wanted to talk about this patient because she felt it had been a positive experience and she felt good about the care she had given the patient and his wife. She described how “the wife was very open” and they were able to talk about his condition and impending death. N2 has found that communication with other families has improved since her experience with Patient A and that Patient B’s wife “wanted to tell me her story” is an occurrence “that I find a lot now.”

N2 was relieved that the wife opened up with her because she heard in report that the wife was critical of the care that Patient B had received while in the hospital and “had some bitter feelings about the healthcare profession. The wife’s remarks and her acceptance of Patient B’s impending death boosted N2’s confidence and comfort in caring for both of them.

He was at another hospital and a nurse there had misread an order…. and that’s pretty much with all of his other co-morbidities going on that pretty much started the end of it. What made me feel better; when she told me that, I realized it wasn’t the care that we were giving it was before. And she (the wife) said, “You know what, it happened, it happened. And it’s in the past, we’re here.” So that made me feel really good.
The wife told N2 how they had agreed it was time to stop aggressive treatments; previously when asked if he wanted the nasogastric tube replaced, he spoke about seeing a “green curtain” which he thought symbolized a sign to continue with treatments. Then he pulled the tube out again the next morning.

So she (the wife) went back in to talk to him and he just was very hard to arouse, but he woke up and he looked at her (said), “It’s red”. And she said, “The curtain’s red?” And he said, “Stop”. And he said, “I’m dying, let me go.” And she said, “I give you permission to go.”

After a conference with the medical team and palliative care was instituted, the patient was transferred out of intensive care to the medical unit. N2 spoke about the wife and patient’s acceptance and preparations for Patient B’s impending death.

They were completely comfortable (with the decision). She got all three of his kids on the phone, so that he could hear them, everyone was on the phone, saying their goodbyes, telling him that it’s okay to go and he just went downhill from there.

The comfort and acceptance the wife displayed made the experience for N2 also feel at ease caring for Patient B and his wife, a direct contrast with the way N2 felt about caring for Patient A two years previously. She felt that she could prepare herself for the death “mentally, physically and emotionally.”

And it was just very nice talking to her you could see, she was just looking at him and holding his hand and talking, she just had this peace about her, which made it really nice.

The openness and dialogue that N2 shared with the wife “was kind of neat”. She felt that “it made me feel special” or connected and she “just didn’t want to leave”. As N2 talked with the wife about their decision she discovered that wife was familiar with palliative care because her mother had been in hospice “and it had made her passing such an easy thing to happen, like easy for her to accept, that she kind of knew what to expect with him and wasn’t scared of it”.
The wife’s acceptance and lack of fear was calming to N2 also. She was able to spend time with the patient and wife and she noted the closeness and tender moments they shared. N2 felt emotional and sentimental when she interacted with the wife who “was holding his hand and as she was talking about how they met”.

When the wife was in there talking about their marriage I did get teary-eyed and I just said well you have such beautiful memories and that’s what’s so wonderful all of these memories.

As they talked about the memories N2 “could see him just squeeze her (the wife) hand”. They discussed that Patient B knew that he wasn’t dying alone and felt their presence at the bedside. The wife said, “You know he’s listening.” and N2 reassured her, “Oh yeah, he’s hearing us.”

It was surprising to the wife that the patient was still alive after so many hours. His wife said, ‘I don’t know why he won’t go, I don’t know why he is holding on. I keep telling him it’s OK, go, go!’ N2 tried to offer comfort, support and reassurance to the wife by suggesting that “everyone goes on their own time, he’s got to have all of his stars lined up correctly”. The wife speculated that maybe the patient was “waiting to know that I’m OK”, but Nurse 2 thought “have you left the room, have you left his side at all?” She thought that “I’ve always heard that some people….. Choose who they want to die around and I was just thinking maybe he thought it was going to be too hard” for his wife to watch him die. N2 asked if she had left the room and the wife responded, “No, I’m scared to leave his side…. but when I have left in the past, I like somebody to be in the room with him.” N2 remembered how bad she had felt when Patient A had died alone and replied, “I’m more than happy to come in and sit with him.”

Later in the afternoon, the patient became agitated and began to repeat the same numbers over and over. N2 and the wife searched for meaning for what the numbers symbolized.
He opened up his eyes and he started saying, “6108, 6108” and he was like adamant about 6108. And she’s like, “OK, OK, 6108.” She’s looking at me and says, “I have no idea what 6108 is.”

They discussed the meaning or symbolism of 6108 and N2 suggested that it could be June 1, 2008. The patient’s continued agitation was upsetting to the wife and N2 called the doctor for an order to increase his pain medication. She had to seek help from her team leader to regulate the intravenous drip because she was unfamiliar with giving the type of pain medication (fentanyl). The increase seemed to be effective in relieving the agitation. N2 discussed with the wife other options if the agitation returned. The wife said that Ativan (anti-anxiety medication) had been difficult to withdraw in the past but she was agreeable to try it if needed because she recognized that they would not need to wean him off since he was dying. N2 reemphasized with the wife to call her if she thought he needed more medication.

At one point she called me back and said, I think he’s in pain; he seems to be grimacing a little bit. So I said Ok, no problem, so there was an order for Dilaudid 2 mg….. And so of course at this point with I only had one other patient, who has passed away on me, it was kind of like I didn’t feel comfortable just making that decision.

She was afraid that the pain medication (Dilaudid) could speed Patient B’s death by decreasing his respirations and did not feel comfortable making that decision on her own. N2 called the physician, apologizing, “I’m really sorry to bother you.” The physician responded, “It’s not bother at all. I thank you for calling me. Any questions you have call me.” The physician’s reassurance and offer of support made her “feel better” because she didn’t feel that she had much experience since she had “only been a nurse for two years” and she knew “that giving him this Dilaudid could do it”.

And I don’t want to feel like I’m the responsible one, I know that it’s going to happen, when it happens, but it’s hard for me to think I could be pushing the envelope.
N2 described how she felt when she prepared the medication, “So of course I’m shaking as I’m drawing it up.” The wife was agreeable to the medication and after N2 explained he could die after she administered the Dilaudid, the wife reassured her “If he goes when you give it, I’m okay with that.”

So I felt like it was ok, but I also felt like she was hoping it would…. which, I can’t say I don’t blame her, but it was very hard for me to do that. It was kind of like I was holding my breath as I’m giving it. He made it through just fine. It did slow down his breathing a little bit; he was definitely less restless.

The extra time N2 was spending with her dying patient and wife was noticed by the other nurses.

I had a different group of nurses (than two years earlier with Patient A), they were older nurses, but it was almost like, “You’re in the room, again?” One nurse, she was like, “You’re spending a lot of time in that room, isn’t he palliative care?”

She didn’t feel supported by the nurses and felt she had to justify the time she was in the room by telling them she was doing a task instead of that she wanted to be there.

I just had to increase his fentanyl and he’s still restless and if you need me I’ll be in there, don’t mind being in there. I was thinking, mind your own business! [laugh]. I was thinking, but yes, I am, what’s the problem?

N2 excused the nurses’ comments by saying, “Then again they didn’t know the whole story.” Returning to school for her bachelor’s degree in nursing has helped N2 gain a greater understanding about the reactions of nurses regarding caring for dying patients.

I had done a paper on palliative care and something I had found in research really hit me, it was talking about how most nurses when they have a palliative care patient, they are afraid to go into the room. They always use the excuse the family’s in there. They are really scared and that’s what I think about people like that. I want to be there. If the family doesn’t want me to be there, of course I’m not going to stay there the whole time and get in their way. If the situation allows me, I want to be there, I’m not going to say I really should check on the patient but the family is there in. I go check on the patient when I think I should.
N2 thinks that her basic nursing school education did not really prepare her for the dying patient and the emotions she felt. She feels that death is not discussed enough and there needs to be more education about death and dying to humanize death.

What I would love is more people would talk about it. I wish in school, in hospital settings, just in the workplace people would talk more about people dying, about going through it.

N2 feels that death “is a subject that people back away from and it doesn’t have to be”. She thinks that is because “people are scared” because there is “a lot of the unknown”. She thinks that “people don’t know how to act” and “they don’t know if they should go into the room or not”. She thinks the lack of communication is that “it’s just easier not to talk about it.” N2 believes that if more people were “aware of just the little things of the little things you can do when you have the time” such as “raising up the feet a little” or “raising up the head” it would help nurses care for the dying.

It puts a human side to death instead of just the patient’s deceased, let’s call the doctor, let’s go in there and clean him up, put in a bag.

N2’s Catholic religion is very important to her and that coupled with a positive experience with her father’s death has framed her outlook regarding death and how she cares for the dying. She does not want anyone to die alone.

I’m very, very proud of my faith and rely on my faith a lot and I think; that has a lot to do with it as well.

N2 has assimilated her personal experiences with death, religion/spirituality and information she has read to shape her nursing practice. She feels that it is important to “look at the family” because caring for the patient includes “taking care of their loved ones”. She believes that the family is “an attachment of the patient” and should not be separated from the patient. Death does not frighten her because it is “another whole life beginning” with “pearly gates and the cherry tree and all of the other deceased people up there.” She thinks that in acute care
“people view things in different ways” because “we are more worried about the patient who needs the most”. She explained that Patient B and his wife needed her most and that is why she spent so much time with them.

Is that they need more medication, do they need more treatments or do they need most of your time, your emotions? And that was my biggest thing, that’s why I did spend a lot of time in that room yesterday because if he did go, I wanted to be there as much as possible, for him, for her…. for me. Just know that he died with people who cared. I don’t know him, but I still cared. I don’t want anyone to die alone.

Patient B was still alive when N2 reported off at 7 PM but she knew it would not be much longer. She remised, “I kind of felt like I wanted to be the one that was there when he passed away.” She said goodbye to the wife and felt better about leaving when she heard that some “family members were coming up from Ocala” so that the wife would not be alone.

**Physician 1**

This participant, identified as P1, is female Hispanic senior resident in Internal Medicine in her late 20s. P1 remembered her conversations with N2 and caring for Patient B and his wife six months prior and then during this last admission for sepsis. Patient B’s condition continued to decline over the course of this admission.

We couldn’t figure out why he had sepsis. We were just treating him with antibiotics and his liver was worse…. his kidneys were becoming worse and his breathing wasn’t doing very well; he had a lot of ascites and he was just going in the wrong direction.

Patient B had had numerous issues and was in a lot of pain. His wife had been at his bedside constantly during this admission and in the past. P1 felt that the patient and his wife were suffering.

And he had a lot of pain and I think he besides all of those issues going on, the pain was the worse issue ever because he was suffering and his wife she was suffering with him because of all of the pain he was having.
The wife was “managing a lot of the situation because he had so many medical problems over the years” and had “learned what medications are which and what to do with him”.

She was very concerned about not giving him pain medication because it will depress his respirations but she wanted the pain to be controlled.

Being truthful with patient and families is important to P1 and it became necessary to initiate a discussion with the wife regarding the patient’s code status because controlling Patient B’s pain could cause respiratory depression. Normally, P1 likes to initiate the discussion of what care the patient wants with the family early to determine if any changes in code status are warranted and plan accordingly. P1 felt that the patient knew that he was dying when she admitted him the last time.

So it was weird situation, but for that particular case that person had so many medical problems and he came in extremely septic, so I think I knew that he wasn’t going to survive this hospitalization.

During her rounds she observed Patient B develop “multiple organ systems failure” and did not improve during his stay in the intensive care unit so she “just kept on visiting with him and the wife”.

I always tell them the truth and when things are not looking good I start telling them pretty early that you know things are not turning around, that they are not going in the right direction.

The dialogue and discussion turned to “talking about code status”.

Do you still want us to do this?’ or ‘you need to have a talk with the patient yourself and see what you guys want to do and be comfortable with the decision.

After the last discussion with the wife regarding the poor prognosis, the patient and wife decided on palliative care and the patient was transferred to a medical unit. The physician team stayed in communication throughout the day with the wife.

Then he moved up to the 5th floor so he actually passed away when everyone said no more interventions. We actually spoke to the wife the same day and we saw her in the afternoon and we kept on checking up the patient.
P1 also spoke of the conversations with the nurse regarding his medications. She wanted the nurse to know that it was acceptable to increase the medications to keep the patient comfortable.

And then we also spoke to the nurse and we told her if you want to go up on the fentanyl and you think it is appropriate, then go ahead and do it. Go up on whatever you can to make him feel comfortable.

She understood the nurse’s need for reassurance in increasing the medications. Her own experience from treating critically ill patients in the intensive care unit has made P1 more confident in giving medications that can have the side effect of depressed respirations if the family is agreeable. While in the intensive care unit she was able to observe the “whole physiology and how medications affect the physiology and once you see all that go together…. I saw that it didn’t affect them as much as I thought it would”.

I think as an intern you are…. I was really afraid of was to give too many narcotics or too many benzodiazepines or any medications that would depress their breathing a lot more. This year I feel a lot more comfortable giving those medications and not that I do it freely, but if the patient’s family members feel that the patient needs a little bit more medication then I titrate it up.

P1 had already left the hospital the night the patient died. She had left her junior resident in charge after she had discussed the plan of care with him to make sure he understood how to keep the patient and wife comfortable. She felt that her team had provided excellent care to both the patient and his wife.

I think it was about 9 pm (when Patient B died). No, I wasn’t there. I had already gone home by that time, but my intern, the junior resident who I was supervising, I gave him specific instructions and we talked about it to make sure that he gets whatever medication that is necessary and to make sure that the wife is comfortable.

**Analysis of Patient B’s death narrative**

Both healthcare providers’ narratives about their experience with Patient B during the last hours of his life illustrate how caring for a dying patient can be a positive experience when there
is harmony and a shared view of the expected outcome among the healthcare providers, patient and family. The wife also had experience with hospice in the recent death of her mother so she was familiar and comfortable with the palliative approach. Everyone was focused on the comfort of the patient and talked freely and openly about death. At each juncture of care, decisions were made together which in turn enabled the nurse, wife and physician feel supported by the other and preserving the patient’s dignity.

Both healthcare providers were comfortable with their role in this death; the nurse had two more years of nursing experience since Patient A’s death and the physician was completing her residency so she had three more years of experience than P1 during Patient A’s death. The nurse had also gained more knowledge of palliative care because she had written a paper on the subject when she returned to school for a bachelor’s degree.

One reason for the harmony in this case versus Patient A was that physician had established rapport and trust over time with the wife because she had cared for the patient over a period of time. She had opened the dialogue with the patient and wife early that he was not improving and began to talk about “code status” when he developed multi-system organ failure. Patient B and the wife made the decision together to stop aggressive treatments. The physician thought that the medical team “provided good care” and “that the wife appreciated” their efforts. She felt that giving the family autonomy made the wife “feel a little bit better” because Patient B was “dying with dignity” and “not suffering.

The nurse was nervous to receive a dying patient as her experience with Patient A’s death, two years earlier had traumatized her because there had been much disharmony; the healthcare providers and the family had not been on the same page. Once she knew that the wife would be with the patient so he would not die alone and had chosen palliative care, she was relieved.
The nurse “humanized” the care she gave sharing her time and emotions while providing comfort to the wife and the patient. She had a sense of satisfaction because she felt she had been a good nurse to the patient and the wife. The physician supported the nurse when she called for reassurance and questions by being respectful and letting her know it was “no bother”. This openness of dialogue between the healthcare providers and family and attention to the comfort of the patient created a sense of tranquility and harmony, which in turn allowed N2 to prepare herself for the patient’s death.

The physician saw her role as a mentor and teacher to both the nurse and her junior resident. She treated all of the parties with respect and compassion because she understood the doubts one can have that lack of experience can produce. She was confident in her ability and her past experiences in the intensive care unit had given her sufficient clinical knowledge to feel comfortable with the medication dosing. She understood that the wife needed the medical team’s ongoing support, even as treatments were discontinued, to provide a presence and support as Patient B died. The harmony that the nurse felt gave her confidence in her ability and helped make this a meaningful experience for her; a death in the hospital could be with family as she had experienced with her own father at home with hospice. She felt that she wanted to be a part of the experience, thus her reluctance to leave at the end of her shift.

The nurse’s story displayed emotional and spiritual components. She talked about her feelings and how she was able to prepare herself emotionally and spiritually for his impending death contrasting the previous experience with Patient A. She felt connected with the wife and spent much of her time in the room with them. She was not afraid of his death, in fact was said that she was disappointed that he was still alive at the end of her shift and would not witness his death.
Patient B died shortly after both the nurse and physician had finished their shifts; they both considered the experience as positive. The physician’s story was told in a very factual and clinical manner, it did not have the spiritual component the nurse’s story possessed; this death did not provoke any intense feelings for her.

Because the nurse, physician and family shared common goals the patient received excellent end of life care. The impending death was discussed openly among the medical staff, nurse and wife. This created an atmosphere in which all felt comfortable and supported and the focus of care was on patient’s comfort. It was a very meaningful experience for the nurse, she did not find the death to be stressful, in fact it seemed to energize her and provide self actualization in understanding her role in providing end of life care.

**Patient C**

Patient C was an elderly lady (80’s) who had been admitted for respiratory failure several days before her death. The family had been approached about considering palliative care and hospice before the weekend, but no decisions had been made. Her condition continued to deteriorate over the weekend and the family had agreed to a limited code status the evening prior to her death, but it was not thought at that time that death was imminent. Patient C’s condition declined rapidly while Nurse 3 and Nursing Assistant 2 cared for her on Monday, culminating into her death in the late afternoon.

**Nurse 3**

This participant identified as N3, is a white female in her late 40’s who has been a nurse over 20 years in the Coronary Care Unit (CCU). She had experienced many deaths of patients while she had worked in CCU, but this was the first death since she had transferred to the medical floor seven months prior. At first she had some trouble remembering the patient; it had been almost two weeks from the death and she had only cared for the patient the day she died.
N3 begins her story by visualizing the experience. She did not consider the day to be “horrible” even though the patient had died during her shift.

I’m trying to remember the day, it was a Monday. I don’t think I had any horrible patients, so it was easy enough to take care of and meet their needs. But it wasn’t a horrible day. I’m sure I spent more time there than any other patient. I didn’t have any major complaints or issues or problems…. I wasn’t screaming and [laugh] it was busy enough.

As she remembered the day and the patient she spoke about how the report she had received regarding the patient’s condition.

From what I had understood she had not progressed well during the course of the stay here and had continued to deteriorate till the point where they finally had talked to the family the night before.

She was told that a “No Code” or “Do Not Resuscitate” order had been obtained from the conversations with the family. But the report “didn’t really make an impression” or alert her that the patient was near death. When N3 went in to see the patient at the beginning of her shift she was surprised at her condition because “she was not real responsive” and “you could see that she was not doing well”.

I kind of considered that she was dying when I first assessed her, I think they said that her pressures were like in the 90s, but when I came in it was 60, but she was able to respond with that still.

N3 was alarmed that the patient’s condition appeared to be deteriorating and did not match the report she had received so she checked the chart. She discovered the information she had received regarding code status was incorrect and that the patient was to be receiving blood pressure medication if needed so she notified the physicians of her findings.

And then so then I looked at the code paperwork and saw that she did need, that we were supposed to be using vasoactives and that so that’s when we called the doctors.

The physicians were prompt in their response and gave her orders for fluids and medications to attempt to raise her blood pressure which “made sense” to N3 as she carried out
their orders. She questioned whether the patient should be transferred to intensive care (ICU) because vasoactive medications were ordered to help maintain her blood pressure. One of the doctors responded, “She’s dying.” Because N3 had coronary care unit experience, she felt comfortable to continue caring for patient on the med-surgical unit as hospice was consulted.

So they decide and I….. to keep her here and run the dopamine as high as you can. It made sense. I gave the bolus and the albumin and pumped the dopamine.

The patient appeared to be in pain but N3 was concerned about medicating for pain because she was afraid that it would further compromise her blood pressure and did not give the medication because the daughter or family decision maker was supposedly on her way to the hospital. The daughter did not come to the hospital until later that afternoon, despite calls from the granddaughter and hospice. N3 felt this delay and lack of clear directives hampered her care of the patient, she “wished” that she had been able to medicate the patient. Other family members visited and N3 talked about the care she gave to the patient and family.

And this whole time her pressure is stayed mostly in the 60s -70s-80s. I’m trying to remember if we gave any other treatments in between, just monitoring her, trying to position…. couldn’t really give pain meds, so tried to reposition her and help her that way. She was mostly out of it. I was able to spend most…. a lot of time in that room. Although….. When the family was in there I tried (to be unobtrusive)… I didn’t want to hover around.

When the daughter (and decision maker) finally came to the hospital and spoke with the patient, she asked for the pain medication. N3 told her that the medication might lower her blood pressure more, so much it could “make her death more imminent”. The daughter spoke with her mother again and consented to the pain medication. Hospice and the hospital social worker took the family away to discuss palliative care as she administered the pain medication.

As they were going off to give the talk, I was giving the pain medicine, by the time they got back, I had no pressure…. And then were acute changes on the telemetry. She had a MI [heart attack]. She bottomed out within 15 minutes and so all of that happened all at once.
The family had agreed to palliative care during the meeting with the hospice nurse and N3 notified the doctor of the changes in the patient’s condition and their verbal consent for hospice admission. The family said their goodbyes and sat at her bedside as she died.

They didn’t really get a chance to sign, but they gave their verbal and hospice said, ‘get the doctor on the phone and get the palliative bed order.’ They wanted the bipap [bi-level positive airway pressure breathing apparatus] removed so they could talk to her and he gave me those orders on the phone right away. By the time we got the bipap off, each of them, I think there was three at the bedside were able to kiss her. And they knew we were losing her at any point. Very quick… within 20 minutes.

The patient’s rapid death surprised N3 and the family. She had thought it would take longer and the rest of the family would have an opportunity to come and say goodbye. She speculated that the family been informed about the poor prognosis but it took them the weekend to process the information because the family “didn’t automatically go to a ‘do not resuscitate’, the family chose limited” (code).

So in my mind that means the family was probably the hold up. They were not ready to say, ‘let’s this happen’. And the family didn’t change until they went and talked with the hospice nurse. It was within the hour of her death. It just seems to me by what I saw that day, that the family wasn’t ready to process.

N3 felt that the family was accepting of her death by the time it occurred because “I didn’t see any of that drama or anything going on amongst them” and “everybody seemed to be on the same page”. Everyone recognized “this is end of life” and they were not “all excited about doing something heroic here”, “let’s just” let nature take its “course… in the kindest way possible”. But N3 “didn’t think it would be that quick” She pondered whether giving the pain medication had speeded up the death by lowering the patient’s blood pressure enough to cause the heart attack.

I still don’t know if that medicine caused her to have an MI [heart attack], I think…. She had the ST elevation [electrocardiogram changes]. Could be what happened. Although, 0.5 of Nuban…. but if it lowered the pressure…. it could be….
But N3 did not feel that the patient’s death was traumatic to her because it was rapid and the rapidity protected the family from feeling guilty about signing the consent for admission to hospice and eventual death.

I was never really super tense. I think not traumatic because to me it almost worked the best way it could, they kind of had made the decision, but they didn’t really have to go through with it…. One of them said, ‘she kind of took the decision out of our hands, didn’t she?’ And they said, yeah she did. The daughter seemed to be relieved to hear that....

N3 thought “that’s the best thing the family can get, is when they don’t have to make that decision” because the patient made it and it would “take that guilt off”. She felt that family was comfortable because “they did what the patient asked for”. She felt that there was not “a lot of drama” and the “family was pretty reasonable”. It was not difficult situation for her either because everyone was in agreement and accepting of the impending death.

N3 talked about how hard it was for a family to make a decision to stop aggressive care, because withdrawing care can cause a family to think that they are “killing” the patient. “No matter how you explain it to them, they know it’s not… It’s still hard to….” She spoke about how hard it had been for her sister when their mother was dying. The guilt and emotional distress her sister experienced was very difficult because she compared signing the consent to withdraw care to signing a death warrant.

Other patient deaths have not been so easy; N3 remembered having a harder time with death when she was a less experienced nurse while working in the coronary care unit.

Actually I’m not upset about this one, so no I haven’t gone home and tormented. You know, I’ve thought about it and it brings back more horror memories from years ago….. Watching people swell up with fluids seeping out all over and still having to…. 

I know I remember in coronary care, when I was a night nurse, I remember wondering, death being new…. looking at them and all the fuss, what is going on, what’s right, what’s wrong? I think I did a lot more soul searching back then.
She felt that this death happened the way it should have, it was “natural” and she “can’t believe that God didn’t intend for people to die” especially when they have lived to “82 or 92”. This patient’s death did not have a negative impact on N3 because the patient and family were accepting and there was harmony among the family and healthcare providers in the plan of care.

**Nursing Assistant 2**

This participant identified as NA2, is a black female who has over 21 years of experience, previously in nursing homes, where a death of a patient was not uncommon. In nursing homes long term relationships were developed with the residents because they cared for the same group of patients each day. She had cared for Patient C only on the day she died so she had not developed a relationship with the patient and family.

NA2 begins her narrative about the experience she had while caring for Patient C. The report that she received from the N3 did not warn her that the patient was dying. NA2 felt she knew that the patient would die soon after she went into the room because the patient’s blood pressure was so low and she was having difficulty breathing. Only minimal care was provided for the patient, emptying the rectal tube and urine catheter and she “just tried to do the best” she could “to make her comfortable.” NA2 felt that the patient was very fragile and she had a hard time communicating with her because she was on an external breathing machine. She knew that it was frustrating to the patient because “she’s trying to breathe” and “you can see it in her face, she’s looking at you and it’s like she wants to tell you something”.

You’re trying to get her to say something or ask her a question and her voice is very raspy. And she couldn’t really get out what she wanted to say.

NA2 found the patient’s breathing difficulties to be disturbing and she tried to make the patient comfortable because “that was the main thing, because we couldn’t do too much”.
Whenever I see someone breathing like that, I kind of like relate to myself because I have asthma, I can understand how they are feeling ‘cause you know… being short of breath... [laugh] It’s not a good feeling.

NA2 did not talk much with the family; she said the nurse talked with the family. The family told the nurse that the patient’s “bottom was hurting”. NA2 assisted the nurse with repositioning and emptying the rectal tube. She felt the patient “looked a little more relieved” and was able to nod her head that she felt better after they finished.

During the day, the patient appeared to be responding to the interventions when her blood pressure increased to “normal” which Nursing Assistant noted made the nurse “happy”. But this improvement was very short lived.

Yes, the funny thing her blood pressure so low and then all of the sudden it was normal. It was just like she was getting better. And everybody was so amazed, even a nurse said that the respiratory therapist, she passed by and took a double look. And she said, “oh my goodness, what a good blood pressure!” Just like she had such a normal 120/60 or something like that. It was a very good blood pressure. And then it dropped back down again [laugh]. So it’s was just like you know got better for a minute.

The patient’s condition deteriorated very rapidly after that. She observed the nurse “running back and forth in the room and calling the doctor.” NA2 saw that she was having more difficulty breathing and knew that the family would be returning. She had difficulty finding the words to describe her thoughts at this time.

I….I…. it’s really….. The words are hard to say; when you see someone you know just who’s ready to go. You wonder what is going on with them ‘cause at one point you know she would look at you and you wonder, ‘What she’s thinking?’ She’s looking at you like she’s asking you to help me or do something. And you trying to do whatever you can do for her, you’re limited when they are fragile like that.

She knew that the patient was dying because “it’s just like I have a sense to see it when I can look at someone.” NA2 had realized the same thing when her own father was sick and in the hospital and said “he’s not going to be here too much longer.” He died that day and “so I looked
at this lady and I could see that she wasn’t going to be here too long.” She was curious about what the patient was thinking and she thought that the patient was not fighting death.

The way she was looking at you it’s like she is staring and like wondering what’s she’s thinking about. I’m looking at her and I she’s looking at me and she’s barely breathing. She has the breathing machine on; it was just covering her whole mouth. She seemed to be tolerating it; it wasn’t like she was fighting it.

The patient’s staring seemed to bother NA2. She mentioned it many times in her narrative. She felt that the patient was suffering due to difficulty breathing and she sympathized with that.

‘Cause she wasn’t responding that way that you could see that she was trying to…. She wasn’t, it’s why I say the way she you know was staring; She was looking at you and I’m looking at her and I’m saying to myself, I wonder what’s she’s thinking or how she’s feeling To me, it looked like she was suffering with breathing and like I said I can relate to that.

NA2 was able to focus on the physiological aspects of death instead of emotional when she observed changes on the heart monitor. Since her recent training to read monitors, she had never watched the heart die and it fascinated her.

So that was another thing to see. To actually sit there and look at the rhythm of the heart monitor, and see how the rate was changing and the rhythms were a little bit different. I had seen that, even though I do monitor. That was the first time, I have never seen anyone actually die that was on the monitor. I felt a little strange because it’s letting you know that that person is going. The heart rate just kept dropping, and it would go to 18 then it would go to 12 and then it would go back up, like she’s fighting it. It’s just like you are feeling for her, and then eventually her heart rate was zero. And you knew she was gone.

She remembered when she watched the monitor it gave her “little chills” and she felt “funny looking back” as she realized “this lady is really going down”. This was different for her because the staff let the patient die without interventions.

Usually you see a heart rate like that everybody running and whatever, but they didn’t do that for her because they…. I think she was a DNR [Do Not Resuscitate]. You saw the line go straight. That’s when I got that funny chill; it made me feel bad for her. But in a way glad ‘cause it seemed like to me that she was suffering.
Nursing Assistant said she “felt bad” for the patient and family but she felt that the patient was finally not suffering anymore; it was good that death came quickly.

And I just felt…. felt bad for them and I felt bad for her. But in a way you could see that she was suffering and it’s not nice to say, but maybe she was better off in that way because she so frail and everything was starting to happen. She just looked like she wasn’t going to last too long if she had to stay in that…. in that way.

NA2 felt that she did a good job caring for this patient, “we made her comfortable and we did all of the tasks we had to do”. She also felt that N3 had also given good care to the patient too, but she wished they could have done more. She reflected that if the patient had been in “better shape “they could have “spruced her up a little more”.

NA2 described how the knowledge that someone had died “puts a damper on your feelings” for the rest of the day. She talked about not going in and seeing if she was peaceful in death and to say goodbye. This is a ritual that she usually does when a patient dies to say goodbye. She described her feelings when she went home that night.

Well, my thoughts was that I had a patient that died. You always go home with that, you think about it, you say she died. ...But you always have that in the back of your mind and when I left that day I went home; I knew that someone had died. It …. puts a little damper to your feelings.

NA2 was very glad that the family was present when the patient died. She talked about how she feels bad when a patient dies without family. She “would love to have her family present” when she dies.

If there’s a patient that doesn’t have a family member, then you feel bad for that person, because you know that they’ve died and you know that the family’s not there.

NA2’s experience evoked feelings of sadness because a person had died, but she felt good about it because the family had been present and she had not died alone. Up until the time of death NA2 was concerned that the patient was suffering and felt inadequate in trying to help due to the communication and breathing problems. Even with all of her past experience with death,
NA2 had never actually watched someone die and her dual role as a monitor tech was new; watching her die on the monitor was a unique experience. She was fascinated as she watched the changing rhythm, until she realized that she was watching a person actually die and “got a little chills”. NA2 was saddened that someone had died, but felt better that the patient’s suffering was over.

**Analysis of Patient C’s death narrative**

Morning report did not indicate that Patient C was actively dying, but the nurse and nursing assistant quickly recognized that the patient was rapidly declining and suffering during their first morning rounds. The report had also said the patient’s family had agreed to a “Do Not Resuscitate Order”. But that information was also incorrect, she was to receive medication to maintain her blood pressure. This inconsistency in the plan of care caused some anxiety for the nurse until the physicians acknowledged that they knew the patient was dying and felt it best to not transfer her to intensive care. The nurse thought this made sense to her and she felt better so she focused on maintaining the blood pressure to allow the family time to gather. The nurse felt comfortable in her role communicating the patient’s changing status with the family and physicians. She focused on the physical and emotional care of the patient and family while carrying out the physicians’ orders. She felt that the patient was in pain, but did not medicate her because she was fearful of the effect on the patient’s very low blood pressure. The nursing assistant assisted the nurse in the physical care to try and make the patient more comfortable.

The nursing assistant spent only minimal time in the room with the patient because she had many other patients that day and she was never alone with the patient. She did not communicate with the family or physicians. The patient’s struggle to breathe was upsetting to the nursing assistant because she has also experienced difficulty breathing with asthma. She also found the patient’s staring unsettling, she wondered what she was thinking or trying to say. She felt like
they had done the best they could in trying to make the patient comfortable, but she felt that the patient was suffering.

The physicians had ordered a hospice consult for a palliative bed, but the daughter who was the decision maker, did not come to the hospital until the afternoon, despite phone calls requesting her to come. This caused some stress for the nurse because she felt that the family needed to be there and clarify the plan of care. As soon as the daughter arrived, the patient communicated that she was in pain and the daughter asked for medication. The nurse warned the daughter that the medication might lower the blood pressure more, causing her to die. The daughter asked her mother if she still wanted the medication and she did even if it might hasten death. The nurse administered the pain medication as the family left the room to talk with Hospice. They returned to the room after verbally agreeing to palliative care. The patient died within 20 minutes with the family at the bedside.

The nurse was surprised that the patient died so rapidly, but felt it had been better for the family. She felt that they might have felt guilty if they signed the paperwork and that the patient’s quick death was less painful for them. She did ponder if the medication she administered hastened the patient’s death but it did not bother her since the family had agreed. She felt that it was natural for an older person to die and was relieved that there was not any “drama”, the family and staff allowed her to die peacefully.

The nursing assistant watched the patient’s heart stop on the monitor. She was cognizant that she watched a person die and it gave her “little chills” at the time. It fascinated her to watch the monitor but she felt strange that no one was reacting to the changes in the heart rhythm. She felt sad that someone had died, but was glad that the patient was not suffering anymore.
In summary, this was not a traumatic experience for either healthcare provider because there was harmony; the sequence of events happened with acceptance by the family, medical and nursing staff. The nurse did experience some anxiety as they waited for the daughter to come to meet with hospice, it was unclear if the daughter realized that her mother was so near death and was avoiding the situation or if she was trying to finish her errands before she came to the hospital because she did not know how long she would be there. The death was sudden, but the experienced healthcare providers recognized the signs of impending death and facilitated a dignified death with her family present. All were saddened by the death, but relieved that the patient was not suffering anymore. The open communication between the nurse and doctors, the nurse and nursing assistant and the acceptance of the family allowed the event to be accepted as natural and part of life.

**Patient D**

Patient D was an elderly woman in respiratory failure. Her death was expected, in fact there had been an episode earlier in the day in which the staff had thought that she had died but she began to breathe again. The family was accepting and had gathered and celebrated her life the evening before her death with wine in her hospital room. She was to be moved to Hospice in the morning, but she died during the night with only her son and daughter at her bedside.

**Nurse 4**

This participant identified as N4, is a white female in her early 30’s who had been a nurse about six months prior to Patient D’s death; N4 began her story talking about her inexperience and the instability of the workplace. She considers herself “a baby nurse” and this was her first encounter with death ever or “basically zero, zero experience with death”. The hospital had recently had a change in management and philosophy, from a secular teaching environment to a Catholic facility. The census had been low and N4 stated that there was always staffing issues”.

These changes as well as her lack of knowledge made this experience uncomfortable for her. She found it difficult to remain calm and unemotional, traits which she equates to competence in a nurse.

She defines her role as a nurse as “completing and carrying out the doctor’s orders so a patient will get better” and she enjoys it because she likes “to see the improvement” and found the death of her patient to be unsettling because she felt unprepared to care for a dying patient.

Nobody ever sits down with and says, ‘okay, do x, y & z, make sure this, make sure that.’ A class would have been great [laugh]. It would make you think about death and dying for yourself.

She really hadn’t thought much about a patient dying before this experience and “wondering” what it was like for the family and thought she would not want “to go through that with my own mother”. She tried to structure her plan of care on what she would want if it had been her mother dying. She remembered thinking, “Oh, please don’t, please not on my shift’, you know it is every nurse’s first thought, I’m sure, not on my shift because it’s hard.”

This was the second night that N4 had cared for Patient D. Her death was not unexpected; in fact, the plans were to transfer the patient to a hospice facility in the morning. Even though the patient was receiving palliative care, the heart monitor was still in place to alert the staff of changes or impending death. N4 described her thoughts.

She was already in the phases of dying, very much so it’s like any moment. I think it had been like two days, almost 24 hours. I want to say almost lifeless, there was a heart beating and she had the mask on, mouth wide open, agonal breathing at that point.

N4 “was definitely okay” with giving morphine every two hours “because everybody knew that she was in the death phase” and “we have no idea what kind of pain she was in”. She focused her care on the family, “maybe checked in a little bit more with the family more frequently to see if they needed anything.”
So it was really more like tending to their needs, making sure that everybody was OK and I think I did a really good job.

The patient’s son had just come in from Costa Rica that evening. N4 found it “soothing” that the patient had “waited for him to come” before she died. The family was prepared as they kept a vigil at the bedside. She thought “it was a good idea” that “somebody had brought in one of those boom boxes and they were playing classical music, relaxing music and it wouldn’t have occurred to me to have done that.”

N4 was answering a phone call from the monitor bank about the changes that were occurring on her patient’s heart monitor when the nursing assistant called to her to come to the room. This upset her and she had trouble remaining calm because she thought “there could have been less drama”

I mean ‘cause when I was on the phone with the monitor bank, the tech she yelled down the hallway, ‘N4 come here, come here!’ I mean I already know what was going on. [Cleared throat] I knew, but I think by her doing that probably unsettled the family members more than necessary. The patients heard that and at one o’clock in the morning so, I didn’t think we needed the drama.

She immediately went to her team leader and said, “What do I do?” She was uncertain what to do next since protocols had not been reviewed with her in her orientation. Another nurse also came into the room to see what was going on and took charge by checking for heart sounds. The emotion that the two family members were displaying was also upsetting to N4 because they “were just waiting to hear” that Patient D was deceased and “they had that look of OK this is it”.

It was very emotional. Just very emotional ‘cause the family members are crying, you kind of feel helpless, you do what you can. You ask them if they need anything, “Can I bring you anything?” “What can I do?”

N4 felt lost and did not know what to do to help the family so she “tried to put myself in the daughter’s shoes” and thought, “If I was going through this with my mother, how would I
want the nurse to be, what would I want the nurse to do?” She felt that answering the questions how she would want to be treated “facilitated a lot of my actions.”

N4 did not want to let the family see her emotions because she thought the family might think she wasn’t capable of supporting them. She feels that if you display too much emotion this could complicate the situation so that the family may become “worried about you”.

You can’t get emotional and you can be there for support and everything like that. You shouldn’t put yourself as a factor in the equation because you know it is about them and the patient.

It was quite evident that she found the post death experience distasteful by her almost guttural sounding “ughhh” as she spoke of talking with the family about body part donation and completing the paperwork. She felt it was too soon to talk to the family immediately after the death.

And then you have to ughhh…. this is morbid, you have to call tissue bank and ughhh…. you see that’s should be changed. At one point after that you have to ask the family members what they want and it just felt like… it was too soon afterwards, to go hey what do you want to do with the body? You know so, I didn’t like that part. You have to find out so but the mere fact that you have to discuss that so soon afterwards I was like ughhh… I’m sorry about your loss, but I have this paper work I have to do. That’s not how I said it but that is how it feels like.

N4 also caught herself comparing the deceased patient with what she would observe in a live patient. When she removed the intravenous catheter, she remembered “looking for any active bleeding” and then realizing “Oh wait there’s not going to be any” because she was dead. She described caring for a dead person as “weird” because “her face had kind of sunk in and she turned cold very, very quickly.” She was unsure of what to do, but relied on her instincts.

Her eyes were still partially opened and I tried to close them. I didn’t know if I was allowed to or not to do, but I tried to close them a little bit. And that was weird. I know I was doing that because I saw it in the movies or something or it’s something you instinctually think okay, I need to close her eyes.
Although she didn’t say she was traumatized by the death, she did use the word “traumatized” in describing what it would be like for a nursing assistant to perform postmortem care. She quickly changed the word traumatized to having “death in your face more.”

That’s a good point about the techs because one of their job functions is to prepare the body, so they are probably a little bit more you know…. traumatized, not traumatized but…. [cleared throat] having to deal with you the…. death in your face more.

She didn’t cry at work that night, but she did cry later, much as she had when there had been a very unexpected and traumatic death on the unit, just weeks earlier (a patient had jumped off the balcony). She feels her inexperience made her want to avoid having a patient who is dying.

I wanted to (cry). But I was like this can wait until later. It the same emotion, it is the same emotional feeling when they had that patient… jump. I cried later. And I know and I know every nurse thought this “thank God it was not my patient”. That’s the first thought you have. So I don’t know I guess there are some people who are really good with dealing with death, but I’m sure that comes with experience.

It was all new to me. It was just the first time. I’m sure somebody who has experienced that some 20 different times, gets a lot more better at it than somebody who has never experienced it before, what the protocol or whatever.

She does feel that as she gains experience as a nurse she will become more self assured and be able to provide emotional support for her patients and families. She equates being calm to self assurance, something that she did not experience while caring for this family and patient during her death.

With any other area besides death, I think I am very well, sympathetic and empathetic. I think I am very good with the emotional support, but of course death and dying is a different subject. I honestly don’t know (what I could have done better). Probably remain more calm myself so that you can focus on what needs to be done for the relatives but I think I did a pretty good job there. Whatever more experience you get, the more calm and self assured you are.
In summary, even though the death of Patient D was expected, it was difficult for N4 because she did not feel that she had enough guidance and experience. She found it upsetting that she was not in control of her feelings and found the experience to be very distasteful and morbid.

**Nursing Assistant 3**

This participant identified as NA3 is a white woman in her early 30’s who has over six years of experience as a nursing assistant, several years in a nursing home and approximately two years in hospitals. NA3 had not taken care of Patient D before the night she died. She has experience caring for dying patients but had never had a patient die as she was giving care. She talked about how all of the staff was upset that the patient was near death and that they did not want to have the patient die on their shift. She said she was comfortable with a patient dying and used her spiritual beliefs for support.

I was told that every time we moved her that her sats (oxygenation) would drop and her BP (blood pressure) would drop and to move her as little as possible. They are so melodramatic about things.… ‘Ok, don’t touch them, don’t move them or else they are going to die…’ The thing is you don’t want a patient to die on your shift. Me…. I’m easy go lucky, if it happens it happens, it is God’s time, and it’s time for you to go.

NA3 knew that this patient was near death because she was “turning blue in her nail beds” and “holding her breath”. She had frightened the staff earlier in the day and was now unresponsive.

From what I was understanding, they thought she had gone earlier that day, but then once they came in she… [took a loud deep breath] Uhhhhh, you know how they do; [laugh] so I think everybody was kind of like on pins and needles with the whole situation.

The staff was only providing minimal care to the patient and only at the family’s request. NA3 focused her care on the family and she felt that she was able to make the family comfortable. She treated them the way she would want to be treated if the patient had been her family member.
So, my concern was making sure that the family was OK, that there was enough juice in there for the family, that everybody was OK, that the patient was clean. I clicked very well with the family, the daughter and the son was there and I made sure that everybody had coffee and juice; do you need a pillow?

She gave extra effort to this family and tried her “best to make them as comfortable” as she could. NA3 empathized with them by treating them as she would like her own “mom or grandma” to be treated by “the people who are taking care of her”. She described the reason she wanted them to be comfortable “because you’re attached, but you’re not attached, so you don’t have the emotional strains” that the family has.

NA3 provided physical care to the patient two different times the night she died at the family’s request. She talked about the conflict that she had with N4 when she asked N4 to assist in cleaning up the patient. N4 was not available to help when she asked. There were differences in priorities, NA3 felt that N4 should have stopped what she was doing and helped her. She reported back to N4 that she had done the care with the assistance of another nurse.

So when… they had called us the first time and told us to come in and clean her up, N4 and I had a contradiction about it. When I went to go take care of her to get her cleaned up N4 wasn’t ready to take care of her and get her cleaned up. It was by the family’s request that it was done because she had soiled herself. So…. she didn’t help me, I had another nurse help me.

The patient did not tolerate the activity of being moved and cleaned, “she got shallowed breathing” but seemed to be all right. The second time the family requested care, NA3 specifically asked the daughter” for permission to move her. She tried to keep it low key and let the family make the decision since she had not tolerated the last movement well.

There’s no stress… it’s their decision and she (the daughter) said, “No problem we’re going to step outside and just let us know when you are finished.”

She went to N4 again and asked for assistance. N4 was again not available so NA3 sought assistance from another staff member. The patient died as NA3 completed the task.
We got her cleaned up and then as soon as I got her cleaned up and laid her back over, she took maybe three or four more breaths and that was it. It upset NA3 that the patient died as she was providing care and she empathized with the family’s loss.

So…. and I felt horrible in a sense because I know the loss that they have and to the fact that you know that your hands were the last hand that touched her. So that kind of plays an emotional trip on you whether you are attached or not attached.

She questioned whether she should have moved the patient since the staff had been avoiding it, “you just have a lot of different things that go on into your mind, or at least I did.” She thought that maybe if she had not been so responsive, the patient may not have died at that moment she was touching her.

But it is just the fact of knowing… well dang, maybe if I wouldn’t have changed her and if I was a slack aide and didn’t stay on top of things like that maybe that would have given her a couple more hours with her family.

But the family assured her, “in all honesty, they were really sweet” that they did not hold her responsible for accelerating the death even after she “kind of teared up”, the daughter said to her, “’No it’s OK, it’s OK, you know I’m glad you cleaned her up.” And she said, “You made her smell so pretty and you know you took really good care of her and we really appreciate it.”

NA3 was still feeling emotional when N4 asked her what had happened. She was already angry that N4 hadn’t helped her and N4’s questions only made the anger intensify because she had already had doubts whether she had accelerated the patient’s death.

And then when N4 turned around came back and was questioning me, cleaning her and turning her. I got irate. And I was like, do you not think that I am not capable of to know not to touch the patient, turn the patient without the patient’s family’s permission?

She felt that N4 had “really insulted” her, which upset her “even more”.

Okay my patient just died. Now I’m the one who has to go in and clean her up and tag her…. you know that’s an emotional thing…. You know you’re dealing with someone who was breathing and living however the case may be and then now you’re having to deal with as being deceased…. 
This altercation with N4 continues to bother NA3, not the patient’s death. “The only thing that really affected me was the confrontation between me and N4.” She feels that fundamentally they have a different philosophy of what is important in patient care.

I’m one of those gung ho people and I’m not saying I know everything, but I’ve got a pretty good brain on me and I’ve had a lot of hands on experience so I just expect, I have high expectations from my coworkers and which I would hope that they expect the same from me.

She did acknowledge that N4 might have been feeling emotional about the death too and that the situation caused the intensity of the confrontation.

For me it probably would have been a stressful situation being a nurse and knowing that your patient could die any second and there is absolutely nothing that you can do about it.

In summary, NA3 still feels that she and N4 have many differences and she has sought guidance through prayer to help her deal with it in the future. NA3 was upset that her hands had been the last to touch the patient prior to death and she felt angry that she had to justify why she moved the patient to N4. The emotional event of a patient’s death amplified the differences and there is a lack of trust between the two.

I had mixed feeling that night, I was really angry at the nurse because she bucked heads so bad and to this day, God forgive me and I know we are supposed to let things go, but we still kind of have conflict on that one when it comes to patient care and stuff. I get really on the defensive with her and I have been praying to God about it to kind of help me deal with that one.

Analysis of Patient D’s death narrative

Patient D’s death was an expected event, although the staff hoped that it would not happen on their shift. It was the first death of a patient for the nurse and she had not experienced a death of any close family member. This caused her to be unsure of how to provide care for the patient and family. The nursing assistant had some previous experience, but had never been present at the moment of death before. The family had accepted the impending death and had “celebrated”
the patient’s life with a party in the room the previous evening. The knowledge and acceptance of the impending death by family and providers did not prevent disharmony erupting between the nurse and nursing assistant when the patient died because they both believed that moving the patient caused her to die sooner and did not realize that this most likely had nothing to do with her death.

The nurse and nursing assistant had very different views of what each other’s role should be and this intensified the emotional feelings and disharmony that erupted after the patient died. The nurse thought calmness and no outward emotional displays signified competent nursing. She focused on the tasks of giving medications and paperwork and delegated the physical care of the patient to the nursing assistant. It is not clear from her narrative why she did not assist the nursing assistant, but it could be speculated that since she was uncomfortable with death she may have used avoidance as a protective mechanism because she was fearful that the patient would die and the staff had avoided moving the patient so that she would not die on their shift. The nursing assistant interpreted the nurse’s unresponsiveness to her requests for assistance as uncaring and poor nursing which intensified her feelings of frustration and anger at the nurse. The nurse did not mention a conflict between her and the nursing assistant in her narrative, but did say that it upset her when the nursing assistant “yelled” down the hall as the patient was dying causing her to feel that maybe others thought she was incompetent as a nurse.

The death was a very unpleasant experience for the new nurse; she did not feel confident and was unprepared to care for a dying patient. The emotions she experienced after the death were unsettling because she did not remain calm. The nurse felt that her education and hospital orientation did not prepare her for a patient’s death. She felt a class on death and dying would have been beneficial to help her feel more comfortable with her role as a nurse when her patient
was dying. She hopes that she can gain more confidence by remaining calm and unemotional in the future.

The nursing assistant harbored angry feelings at the nurse because she felt that she had been negligent in her role of caring for the patient because she had not assisted in the care. The assistant felt guilty that her turning of the patient had caused the patient to die. When the nurse questioned what happened, the assistant became defensive and her anger escalated because if the nurse had been there (like she thought the nurse should have) she would have known that it was not her fault that the patient died on their shift. The nursing assistant learned that she needed to put her own feelings aside and work with the nurse in the future for the sake of the patients. She reflected that maybe the nurse’s fear and lack of experience may have contributed to her actions and attitude.

In summary these narratives illustrate that disharmony can occur among the staff because of fear and uncertainty even if the death is anticipated. The lack of experience and confidence of the nurse caused the nursing assistant to think that the nurse was uncaring and unprofessional. The nurse avoided what she was not comfortable with, and the nursing assistant felt resentful that she was carrying the burden of caring for the dying patient. This resentment could also be related to the organizational structure of the hospital regarding role definition and responsibility. The nursing assistant did not comprehend all of the responsibilities that the nurse had and her view of the nurse was framed in what she felt was good patient care, bedside nursing. When the patient did not receive the care from the nurse that the assistant thought she should, the assistant harbored feelings of anger that erupted in an exchange between the two after the death when she felt the nurse blamed her for hastening the death.
Patient E & Nurse 1

Patient E was a black man in his 50’s who died from liver transplant failure. Nurse 1 (N1) is a white Catholic female in her early 50’s and she cared for Patient E the last night of his life. She had developed a special bond with the patient and wife over a two year period that she cared for Patient E throughout many previous hospitalizations including two liver transplants. The story that N1 told during the interview was about her relationship with them and how she shared in their suffering. Although she didn’t say the word love, she did feel that they were “like family” because they had shared conversations about each other’s family members and prayed together.

I had become very close to both this man (the patient) and his wife. I had met him before he was actually transplanted. The wife used to come, even if I didn’t have him as a patient, used to come find me. I’d be taking care of other patients; she’d want me to go pray with him or would tell me what was going on with her husband or whatever he had. I would go in and we would talk about the different things he’d talk about his daughter and his son and all that kind of stuff I’d tell him about my son and we’d be talking all the time. They became like family.

N1 respected Patient E because “He was very, very intelligent man and very outgoing, very smart”. This long term close relationship with the patient made his death difficult for N1 because he had been “such a go-getter and he had so much life to him…. when he wasn’t really all that sick”. She had watched him decline for months to become “just a shell” of the man he had been before. It seemed to be the hardest for N1 when his neurological status “had just decompensated to such a horrible degree” and they weren’t able to converse as before but she would “just go in and tell him my stories”. She reflected that she had watched him progress through the stages of dying.

So it was very, very difficult because we watched him go through all kinds of changes. Completely deteriorating…. how he was dying inches. He went through all of the stages. He went through the denial, the anger. He went through all those stages; you could see it all. And being part of that it was difficult to watch.
The patient’s deterioration was also difficult for the family because they “didn’t want to give up on him, initially” and the medical team was “doing all kinds of treatments to keep him alive”. N1 spoke of the faith that the wife had that “God was going to perform a miracle and that he was going to be cured” but she was willing to “accept whatever needed to be”. She described how the family supported one another.

But it was the kids that were having such a hard time and it turned out to be the kids were the ones the support for her (the wife). She was the one who actually broke down. Finally they decided that this would be enough. He had suffered enough. Actually it was good that the kids got to see how really bad he was and I think they were probably grateful by the time he died.

N1 was grateful when the “family was finally saying enough was enough…. because we had all thought that they probably should have given up much sooner than they actually did but thought “they all needed time to deal with it”.

There was also some reluctance in the medical staff to accept that the patient was dying as evidenced by the talk of attempting a third transplant. N1 and her colleagues were grateful that the team changed their approach from aggressive treatments to palliative care. She found solitude by feeling that his death “was a blessing” so he didn’t have to suffer any more. She felt after palliative care was initiated, the patient “was finally resigned to the fact that he was going to die” and “he had peace”.

We were just so grateful that they didn’t give him another one (transplant). It would have been horrible. There was no way he could have survived it. Nothing was going to help him so they decided to put him on hospice. But I really think it was a blessing that he did die.

It was important to N1 that the patient and family did not be abandoned by the team once palliative care had been initiated. She felt that the patient and family would get better care and support from the hospital staff that knew them so well than from unfamiliar staff in hospice or in their home which was several hours away.
They were going to transfer him out and they decided no, but they were just going to let him stay where he was. And that he really needed to die with us at the hospital because we were the ones who were giving her the support. We were the ones who were giving him the care that he needed. She (the wife) was grateful for the fact that they were allowing him to die there. Taking him out of the hospital and having him die at home would not be as beneficial to him or to them.

N1 was assigned to care for Patient E the last night of his life. Her spirituality is evident in that she felt blessed that it “was a slow” night and she was able to focus on the care of Patient E during their last hours together. N1 described her tasks that night as “basically comfort care” which included “turning and positioning him” and “a lot of family interaction”. There was “a lot of verbalizing but the actual care was the same of any dying patient.” She described how she altered her normal routine that night by trying “to get the other patients taken care of as quickly as possible”.

Normally I spend a lot of time talking with my patients. I do a lot of extra things like backrubs, and all that kind of stuff. But instead what I did was get as much done as I could so I could be available. I tried to get my charting up to date, as much as I could in case he did go down more or he did die, so I could be available because he was so close to dying I was hoping that I would be there with him when he passed.

The wife wanted to go home and rest but she was very particular in how she wanted Patient E’s care. N1 “spent a lot of time with her to make sure that she knew that I knew exactly what she wanted and that I would carry on what she wanted.” She prayed with the family. She tried to be supportive and be reassuring that he would receive excellent care. N1 was very protective of her patient and the family did not have other staff to assist her in the physical tasks because the nursing assistant who was assigned that night was “one of those rough people” who “couldn’t be bothered” with giving meticulous care to her patients. The nursing assistant’s rushed demeanor and attitude bothered N1 and she “felt that if she was upsetting me, she would really be upsetting the family. [Laugh] She was upsetting me, because I knew she didn’t want to be there” (with a dying patient).
And I let the daughter stay in the room when we went in to turn and position. The daughter and I ended up taking care of him. She talked about her father the kind of father he was. I prayed with the daughter and the patient. I had prayed with the wife before she went home.

N1 believes that caring for a dying patient is important, not only for the patient but for the family. She wanted to be with this patient and family at the time of death. Her religion and spirituality shapes her belief that death is a significant part of life.

To me it is an honor to be with someone when they pass. Because it is the most important part of life is at the death. I am a very religious person and not only to be there for the person who is dying, but also to be there for the family.

But the patient did not die during her shift. She spent the day at home thinking and praying for the patient and family, “hoping that I would be there” when he died. She was anticipating that she would care for him when she returned to work at night.

All day long I had been thinking about going in because I knew that he was going to die that day. I felt myself praying for them. I was looking forward to going in. I knew that I was going to have him that night. I had told them the night before; if he was still alive I wanted him as my patient. So I knew that I was going to have him.

As soon as she returned the next evening and “walked in on the floor and I saw that the room was empty.” The patient had “died about an hour and half before” her shift and the family had already left so she did not get to see them. She described her conflicting emotions that the patient had died before she returned. She was relieved and guilty at the same time.

I felt like I should have been there and I know that it is all up to God. I’m sure that was the best thing that could have happened for the family at that time, things needed to be the way they needed to be. But I felt guilty that I wasn’t there…. But at the same token I was relieved, especially when I found out from the nurse who had had him what a mess it was because, the family was hysterical, crying and they were carrying on and they didn’t want to leave.

N1 was distressed to find out that the nurse assigned to the patient was a float nurse and she did not know the patient and family. She felt that the patient and family were let down because they had chosen to remain at the hospital to die in familiar surroundings with familiar
people instead of leaving and going to hospice or home. She was angry with the team leader who had made the assignment and “felt so bad that they gave him that float nurse” because “of course she didn’t know the family”.

She couldn’t take care of her other patients and all that kind of stuff because she had to be with them I didn’t think that was right at all because they knew that he was dying. They really should have assigned a staff member to take care of his family, knowing that he was going to die….

N1 processed her feelings about the patient’s death the rest of the night. N1 felt that it was wrong that an unfamiliar nurse had been assigned to the patient because “it was such a needy family.” She kept repeating, “I just think; it was wrong that they did that. It was wrong.” She was concerned for the family and other transplant patients who came to provide support to the family, knowing that it could have been them. She asked the float nurse to tell her “all of the details” because she needed “to know what had happened”.

I wanted to know how the family reacted. I found out that there were other transplant patients there with them I was wondering how they really reacted knowing that they could be in the same boat too… because everything (life) is so tenuous too.

During the night she talked with other nurses and staff about her feelings and regrets that she wasn’t present at time of death. The staff supported her by pointing out that it was out of her control.

We kept on talking about it I kept thinking I should have been there. I really felt that I should have been there. And they kept on saying, “It’s not up to you”. [Laugh] “You have no control over the situation.” [Laugh] You have no control, when it is his time to go; it is his time to go.

Her laughter during the telling of her feelings that night suggests that she is processing the fact that she does not have control and is accepting or letting it go. Remembering the things she did have control of brought N1 comfort. She felt that he knew that she cared about him and was present his last night alive.
I did have comfort in the fact that I did take such good care of him the night before. I did pray with him, he was alert when I left. He knew that it was me. I mean that he wasn’t talking but he knew. He said my name and he recognized me and he knew that it was me who taking care of him that kind of makes you feel good inside. It was an acknowledgement.

N1 summarizes her feelings and relationship she had with the patient and the impact it had on her. She elaborated why caring for this patient as he died was so significant to her.

Sometime I think you are closer to certain patients than you are to others. I think the emotional connection was stronger because I had known them for so long; he had been in and out so many times. And I think too, because I knew that he was a religious man, a religious person. I felt comfortable crying with them, because I knew that they were religious, where lots of times you don’t know where people are in their journey. You just got to be careful nowadays. We used to go in and pray with everybody and it wasn’t so much a big deal…. Now you feel like people report you if they think you are too religious. So you just wonder where people are in their spiritual journey.

In summary, the death of this patient had a significant impact on N1 as evidenced by her thoughts and prayers. She had tears and joy while caring for him and his family during his journey. They had shared three momentous events in his life, two transplants or rebirths and his death. Sharing these events has left a lasting effect on her. Her faith and spirituality renews her so that she can return to work and care for her patients each day. Nursing is not a job to N1, it is her vocation.

I think I did pretty much what I needed to do for him and the family. I really enjoyed taking care of this patient, I really enjoyed being with the family. I just said I wish that I had been there for them in the end. It will be a patient that I will remember all of my life. Not only him, but also his wife. I still pray for him every day, I do consider them to be family because I still pray for them every day. My faith is what keeps me going. I don’t consider nursing a job, it’s my vocation. I think that I’m here to do God’s work. It is my faith that rekindles me. But it is my faith that keeps me going.

**Analysis of Patient E’s death narrative.** The nurse felt that this patient was “special”, but the emotional toll that she experienced from this patient’s death along with other personal issues has prevented her from becoming as emotionally involved with subsequent patients. N1 believes
her role as a nurse is holistic and a nurse should provide excellent physical and spiritual care to her patients. She believes that nursing is her vocation, not a profession and prays that God will place her in the position that she can help those most in need of spiritual support and prayer.

N1 doesn’t feel that a lot of other healthcare providers share her views of providing the spiritual care and that many do not see the importance of end of life care as evidenced by her diverting the nursing assistant from caring for her dying patient because she thought that she was too rough and “couldn’t be bothered” to take the time the patient required. She was also angry that the team leader had assigned a “float nurse” when the patient died. She felt that the hospital had let the family and patient down since they had chosen to stay in the hospital for his death so that they could be with the staff they had developed a strong relationship in the previous hospitalizations, in essence she felt others did not care as much as she did. Her coworkers did provide her with comfort and support when she talked about her feelings that the patient had died before her next shift and she wasn’t there.

This narrative shows how disharmony may occur when there are different opinions among the family and healthcare providers about the treatment plan. This disharmony may result in suffering. The nurse was suffering as she watched the patient endure what she thought were countless ineffective and painful treatments because the medical team and family were reluctant to give up on a cure. She was very close to the patient and family and this made her suffering greater as she watched the patient as he was “dying in inches”. The family suffered as they watched the patient deteriorate and prayed for a miracle. N1 described how the patient appeared to be at peace with the decision to let him die in the hospital with the staff who he and the wife felt comfortable. The patient died only after his family and the physicians accepted it and harmony was restored.
Patient F & Physician 2

Physician 2 (P2) is a hospitalist and an attending in the Department of Internal Medicine of a teaching hospital. He is a 40ish Jewish male. He is an experienced physician and self professed palliative care advocate who frequently deals with end of life issues. Patient F was female in her 50’s who died of total body organ failure after repeatedly defying death from terminal cancer, sepsis and stroke, surprising everyone. The patient let her family know her wishes that she wanted everything done to prolong her life at the beginning of her illness. She had major surgery and her recovery was stunted by several bouts of infection and complications. P2 spoke about how she was slowly dying and that withdrawal of care was discussed with the family.

And anyway, she was in the unit for a while, and just everyone looked at her said, “She’s dying, we gotta withdraw care.” The family stood based upon what the patient said before surgery to do absolutely everything for as long as it takes. Period. And they fought the ICU forever, for weeks. And then they transferred her to the floor and then the internal medicine service where they fought there for weeks.

Patient F recovered enough to be transferred to a rehab hospital and “according to the family” she recovered enough to have “a wonderful summer”. P2 saw her again in the clinic before she came in to have more extensive surgery in hopes of prolonging her life expectancy. “She was very realistic, but did not want hospice.” The surgery did not go well. P2 again went to the family to discuss palliative care for pain control because she was suffering.

She had declined horrifically in the time and was very encephalopathic, screaming out in agonizing pain. She developed a decubitus ulcer that was rapidly blossoming into one of the worse I’d ever seen. Once again I came to the family and I said I’m not real happy with doing this, I feel like we you know need to get her pain under control. I’m concerned that if we do that we will knock her out and then she’ll die from that. So we have to make some really hard decisions. And the family was very stalwart and said no. That’s not what she wanted.
The patient’s suffering was hard for the staff and family, “every day we watched her suffer more.” P2 rotated off the service and when he came back several months later she was still in the hospital.

She declined even further at that point, getting sicker and sicker and had not had any real moments of salience. So, finally it looked like the family were becoming worn out and recognized that she did not appear to be showing any signs of who she really is anymore. And they were starting to get used to the ideas of the differences in care, changes in care.

P2 approached the family again about withdrawal of care, beginning with a “Do Not Resuscitate Order, which took about a week for them to finally embrace, saying if she got worse that we wouldn’t bring her back.” P2 was willing to continue the aggressive care at that point because she did not seem to be suffering and left it to family to decide.

You guys need to decide among yourselves if there is going to be sign that she gives you, that will make you say, “You know what, let’s stop dialysis.” And everyone agreed that they would keep an eye out for a sign.

After about a week of waiting for a “sign” it came, “she developed an acute stroke and what little consciousness she had was gone.” P2 told the family, “this is your sign and it’s time for withdrawal” of care. Much to P2’s chagrin, after the family had agreed to withdrawal of care, the patient appeared to be getting better once again.

So no sooner that we had gotten them to agree with that, we went into the room and she hugged her daughter and she started talking to them. And I’m like …. What the fuck is this? [Laughter] And here, I’d finally gotten them on the right page, which I think seemed to fit. We’d honored the patient’s wishes to do everything we could, and we had. And now she had major irreversible brain damage. And so the family then said, “Oh you’re wrong again, let’s get a neurologist involved.”

The neurologist supported P2’s assessment, that the stroke was very extensive. The family continued to struggle with deciding what they should do and “there was a rift that occurred in the family”. The son made the decision to withdraw dialysis and parental nutrition and the patient died in 24 hours. P2 described how he felt about the patient’s death.
And the whole process left me mentally exhausted as to how right was I to push as hard as I did. I felt, up until the stroke, I really didn’t feel like that I was 100% certain I could say, she had no hope of recovery. She just really had a long road ahead of her. The stroke put the icing on the cake and made it very easy for me to recommend that, but then just after we diagnosed that, she shows the sign of possibly being able to fight back from that too. It was demoralizing. It made me wonder whether or not I was in the wrong to advocate withdrawal of care and hospice.

This patient’s death was harder for P2 than other patients who he has cared for at end of life because she kept surprising everyone with her resiliency to recover against the odds; it made him question if other patients had had the opportunity to fight, would they have lived longer? He found that talking with the family after the death helped him cope with his feelings because everyone agreed that Patient F had died peacefully.

I waited a few days after her death and I called the family, to talk to them about it. And it was very helpful because we ended up on the same pages of doubt that some of the family members had. But there was uniformity in the fact that the family felt that she had died peacefully. That was very important to me. But it does call into question, do I actually know what the hell I am saying when I tell people that they are about to die. Cause, I…. probably am wrong, I just don’t know how often.

This experience has caused P2 to reflect on his role as a hospitalist because he found this experience to be so difficult. He questions whether he may have been too quick to suggest palliative care.

And it really made me wonder, how many people have I sent to hospice who could have had this other, these moments, where they came back and had more time.... But I gave up, maybe I did give up. So that was a particularly brutal one.

P2 talked about another patient who also had metastatic disease, was on the service about the same time, and had recovered; it made him question himself too.

We had with this other patient, a 20 year old, who had widely metastatic colon cancer, who became septic, following a liver operation to try and remove some mets (cancer). (She) went to the unit and basically had no detectable blood pressures, except on the arterial line and agonal respirations. She failed the vent test, where they turned off the vent and withdrew care. And as the night went on, she continued to breathe agonally. Then she started breathing more normally. And then a week later, she was discharged from the hospital.
This patient’s recovery amazed everyone and P2 found the experience to be “humbling” and he felt “dumb” that he believed she was going to die and didn’t. A television news station interviewed him and asked if her recovery had been a miracle.

And I said, yeah, in the stage of things; it was miraculous. It calls into question a lot of what we believe firmly and clearly. I believe that I do not know everything that my senses and my brain tell me is there. I don’t believe that we…. I’m not a religious person. I’m a spiritual person. And I have seen like patients right before they die, where you’d…. they’re gone. You can look at them, they’re breathing, but they’re gone. And you can feel that. That thing is gone from the patient. So do I believe in miracles? I believe that nothing is fully impossible, but I work in a world of probabilities. So you know at the quantum level of physics, shit happens, it’s so weird. That it’s almost unexplainable. Can that get amplified into the macroscopic world we see, it’s almost impossible events. Do I think that it is directed by spirituality or will, I just don’t know? I think a lot of it has to do with the fact that things happen. Good people, who have every reason to recover, die all the time and we don’t think twice about them. We think twice about the ones who we said were going to die, but didn’t. But the ones we thought who’d get better but died, it doesn’t seem like a miracle to us, right? Maybe it is.

These two experiences have had a significant impact on his practice and how he counsels patients and families.

Well it’s definitely still got echoes in my current practice. I guess what I have learned is that I’ve been much more cautious about stating that this situation will lead to yadddddeydhah. People ask, “Have you seen miracles?” I often will say, “In my experience, I think that have seen situations that were miraculous.”

P2 remembered a statement about death that someone once told him and uses that premise to try and make each experience more meaningful to him and the patient.

So I think the thing that made me realize that I need to focus on this, is because it’s what one person once said, “The thing about death, the thing about living is that no one gets out alive.” And I think that is a very profound statement. So how can I make that more meaningful for me and how can I then (make) it more meaningful for my patients?

**Analysis of Patient F’s death narrative.** The physician described the disharmony that surrounded this case when the patient and family refused to accept palliative care when the healthcare providers thought the patient was suffering and slowly dying. He experienced moral
distress because he fought so hard to try and make the family agree to withdrawal of care. He did not feel that it was ethically correct to continue to allow the patient to suffer. When the patient rallied again after he felt the family was beginning to accept allowing the patient to die, it created more disharmony and distress. The family member who had the patient’s power of attorney decided to stop treatments and withdraw care and the patient died peacefully. In the end everyone agreed that the patient had died peacefully so the family could begin to heal.

The physician questioned his judgment for suggesting palliative care for not only this patient but many others after Patient F seemed to defy death one more time. He wondered whether some of his other patients would have had more time had he given them more of a chance for treatment instead of pushing for hospice. One of the things that complicated this case for the physician was that at the same time, another patient had defied death, so much it was considered a miracle by many. These two cases made a definite impact on this physician. He is now more cautious about “stating what the situation will lead to” and he uses phrases like “in my experience”.

**Summary**

In Level 4 of Riessman’s method of narrative analysis, the retelling is intertwined with the analysis. This section of the chapter presented the narratives of each participant’s experience grouped with the patient whom they shared, followed by a summary narrative analysis as interpreted by this researcher. These findings and those of the other two research questions will be discussed in the summary of findings at the end of this chapter. In the next section the second research question is discussed.

**Influences in HCP’s View of Role – Research Question #2**

Each healthcare provider interviewed had a conception of his or her role in caring for a dying patient from their previous experiences with death, experience and education. This section
will discuss the data from the narratives as whether the experience had any effect on the healthcare providers’ view of their professional role in caring for a dying patient in a medical surgical unit. In this section the participants have been grouped together by their roles to compare, contrast and to examine what factors contribute to the meaningfulness of the experience to address the second research question, *how did this experience influence the healthcare provider’s view of his/her role as a professional caregiver?* This section will also explore what each participant learned or took away from the experience to influence their perception of their role in caring for a dying patient.

**The Nurses**

The data in this study suggests that all of the nurses gained insight regarding their role as a general medical-surgical unit nurse who occasionally cares for the dying patient and family. Each nurse learned things about herself and death because caring for a dying patient is not common on the medical surgical unit. Three of the patient deaths were firsts for the nurses even though each had been working in the same unit for at least six months prior.

All of the nurses felt that providing emotional support to the patients and families was an important part of their role as a nurse. Nurse 4 who described herself as a “baby nurse” due to her lack of experience did not know how to provide emotional support to the family of her dying patient. She said that caring for a dying patient or post death procedures had not been covered in her generic nursing school or hospital orientation. She tried to imagine what she would want from the nurse if it was her mother who was dying but felt uncomfortable and did not feel that she was adequately prepared by her education and orientation for this new experience. Patient D’s death made her realize that she needed more guidance and education in talking with the family to know how to provide emotional support to the family. She found the whole process of postmortem care and paperwork as distasteful or “morbid”. She felt a class on caring for patients
at the end of life would help her feel more prepared to deal with the next death but knows she does not like caring for dying patients; she prefers to care for patients who will get better because she is comfortable in that role.

Nurse 2 in her first narrative about Patient A described how she thought she was prepared to provide care to a dying patient because she had participated in the care of her father at home with hospice, even though she had only been an RN a few months. Unfortunately, she was totally unprepared to deal with the disharmony among the healthcare providers and family when the family would not accept palliative care. Nurse 2 felt that she had not been a very good patient advocate because she did not discuss her opinion of the patient’s status with the family when they asked because she lacked confidence in her assessment skills. The family had felt comfortable to go home because they were hopeful the proposed tests would show improvement in Patient A’s condition. When the patient died alone later, Nurse 2 felt guilty that she had not facilitated more dialogue with the family and had not been the patient’s advocate. She stated that she learned how important it was for documentation of vital signs to reflect the patient’s true status and communicate her feelings and assessments to the medical team.

Nurse 2 felt that Patient A’s death caused her to suffer from post-traumatic stress disorder; she kept replaying it over and over in her mind and could not sleep. She questioned whether her choice of nursing was the right profession for her. Talking with her mother, an experienced oncology and hospice nurse, helped her deal with her feelings. She purposively selected palliative care as a topic for a paper when she returned to school to complete her bachelor’s degree in nursing so that she could learn more about how to care for the dying. During the next two years she gained more confidence in her skills as a nurse and found that she was able to provide emotional support to her patients and families by being present and allowing them to tell
her their stories as she did with Patient B’s wife. Nurse 2 was very comfortable caring for the Patient B who died the night before our interview and she viewed it as very positive experience. There was harmony because everyone was focused on the comfort of the patient and providing support to the wife where as in the death of Patient A there was severe disharmony.

Patient C’s death was the first death of a patient for Nurse 3 since she had transferred to the medical surgical unit after working most of her 20+ year career in the coronary care unit (CCU). She talked about her experiences with patients who had died in CCU and she thought that most had “horrible” or unnatural deaths. Nurse 3 worked hard to maintain harmony among the family and physicians to ensure that Patient C and her family’s needs were met. She maintained the patient’s blood pressure with medication and fluids as she waited for the daughter to give informed consent before she medicated her for pain. She felt that the patient made the decision to die before the daughter could sign the paperwork, thus preventing the daughter from feeling guilty. Nurse 3 provided her presence as a means for emotional support for the family during the patient’s death. The death was peaceful with the family at the patient’s bedside, reinforcing Nurse 3’s perception of how a good death could take place in a hospital, without futile and painful interventions, naturally with family present. She felt that she was able to talk openly with the family and be an advocate for the dying patient and family.

Nurse 1 has cared for many dying patients during her 30 years in the medical surgical and intensive care units. She feels that her role in nursing is not her job but her vocation or calling. She especially enjoys caring for patients at end of life, frequently requesting to be assigned to the dying patient. She believes that spiritual care is important and views her role as holistic in caring for the patient and family. Nurse 1 prays each day before work to God to place her where he needs her the most. She is very attuned to the comfort needs of her patients because she was once
gravely ill and near death and she has also cared for several family members in her own home as they died in hospice care. Patient E’s death was very difficult because she had a very close relationship with the patient and wife. She felt that they were “like family” because they had shared so much over the course of two years during the patient’s many hospitalizations and decline. This death made Nurse 1 realize that she could not control when and who was present when a patient died. She had to let go of her anger that an unfamiliar nurse had been assigned to the patient when he died. She was frustrated because she had worked so hard to create harmony by being supportive to the patient and family and felt that he died with less than optimal circumstances under the care of a stranger who might not be able to meet the needs of the patient and family the way she felt she could. Nurse 1 spent several weeks thinking and praying about Patient E and his family prior to our interview. She recognizes now that because she was so close to them she had to give herself time to grieve. She recently had another health scare and states that she has not had the opportunity or desire to become that close to a patient or family, she works her shift and does her best but tries to leave her emotions at work, instead focusing her off time on activities with her church.

In summary, each nurse interviewed for this study felt that they had gained something from caring for the dying patient and this experience would have an impact on the care each gave to future patients. This was most clearly displayed in Nurse 2 as she reflected on caring for the two patients, two years apart. She showed tremendous growth in her perceptions of her role in caring for a dying patient from her experiences with Patient A and Patient B. Nurse 1 learned accept that she cannot control every aspect of a patient’s death and that being too close to the patient and family is painful for her so she has avoided becoming close to subsequent patients. Nurse 3 learned that she did not like caring for the dying and would prefer to care for patients who will
recover. Nurse 4 now views that it is her role to facilitate communication with the family and the other healthcare providers and that a death in the hospital can happen with harmony and peacefulness. Each nurse was able to verbalize how the experience had changed their perceptions of their roles in caring for the dying.

**The Physicians**

Physicians as a general rule are not present at a patient’s death unless they are participating in revival or withdrawal of care procedures. They see patients and families briefly, write orders and leave. All of the physicians in their narratives saw their role as a guide to help the patient and family accept impending death. The two experienced physicians, Physician 1 and Physician 2 had cared for their patients and families over a period of time and had developed a rapport. The decision to change the plan of care to palliative had been a process, in which the family had time to accept and adapt. Both patients died a peaceful death within 24 hours after withdrawal of aggressive treatments.

Physician 1 did not disclose specifically what impact the death of Patient B had on her view of her role as a physician caring for a dying patient other than she felt that she had provided good care so that the patient was able to die with dignity. She talked about another instance, as a junior resident, where she was distressed when a family blamed her for a poor prognosis because she did not diagnose terminal lung cancer during routine examinations. This negative experience and disharmony caused a significant amount of distress in Physician 1, and she too questioned if this was the right profession for her because originally she had considered oncology. She made the decision to change her specialty and was planning a fellowship in the upcoming year in Infectious Disease Medicine. She did discuss in her interview how she had to come to terms with dealing with families and patients at end of life and learned to set goals to promote autonomy and protect the patient’s dignity by prescribing enough medication for pain relief. She saw her
role as a guide for the family and mentor to less experienced staff to achieve these goals which creates a sense of harmony.

Patient F’s death was one of many experienced by Physician 2, a self proclaimed palliative care advocate; he is quite comfortable broaching the subject with his patients early because he feels many “patients at the end of their lives…do not understand that they may be imminently dying”. Patient F’s ability to rebound several times from serious complications and infections surprised all of the healthcare providers. Physician 2 described the disharmony throughout the course of her hospitalization because Patient F suffered greatly which was very hard for the hospital staff as they watched her die a slow painful death. Physician 2 and others talked extensively with the family to consider withdrawal of care but they were adamant to follow the patient’s wishes and continue aggressive care. After a serious stroke, he got the family to embrace the concept that if she got worse they would not bring her back. “The whole process left” Physician 2 “mentally exhausted” because he questioned his own actions to push for palliative care after she suddenly appeared to rebound again by waking up and talking with her daughter. This created a rift within the family, but after the neurologist confirmed the extent of the stroke, the son decided to withdraw aggressive measures and the patient died within 24 hours. Physician 2 described feeling “demoralized” and he questioned, “Whether or not I was in the wrong to advocate withdrawal of care and hospice?” This case made him “wonder, how many people have I sent to hospice who could have had ….more time?” He states that this death and another patient who refused to die “still echoes” in his current practice and he has learned to be “much more cautious about stating that this situation will lead to yadddeydha”. He now uses terms like “in my experience” in discussing a grave prognosis.
Unfortunately Physician 3 did not have the luxury of time to facilitate family acceptance of impending death before Patient A died 18 hours after admission. He also did not have the experience or knowledge about signs of impending death to support a palliative care plan because he was in the first month of his internship. When the son came to him searching for hope that Patient A was not dying, Physician 3 thought that by promising more diagnostic tests would give him more time to prepare the family. He learned that it was uncomfortable to have to go back and tell the family that the tests would not be done because they would not provide any new information. He is now more cautious in suggesting treatments or tests if he is unsure of the benefit. The interview for this study was two years after the death of Patient A and Physician 3 feels he is much more astute in recognizing the signs of impending death since he has gained much more experience. He feels this patient’s death and other crucial decision making points will “stick with you for the rest of your life because it is going to happen again sometime and you will have it as a reference.”

In summary, all three of these physicians viewed their role at end of life to be a communicator and guide to the patients and families. At end of life frequently the communication is with the family and their wishes are followed. The physicians in this study tried to bring everyone into an agreement in the plan of care to create harmony. When there is disharmony as Physician 2 and Physician 1 described when the patient, family and staff are not “on the same page” of the careplan, was very stressful for the physician. For some this caused them to reevaluate why they chose medicine.

The Nursing Assistants

The nursing assistants were very clear in their understanding of their role when caring for a patient at end of life. They focused their efforts on comfort and attending to hygiene of the patient. They interacted only minimally with family, often offering something to drink and spent
little time in the patients’ room because they had many other patients to attend to. All had previous experiences with death.

Nursing Assistant 1 believed her role was to attend to the needs of the patient and “get out” and “not get caught up” in the drama or disharmony that was unfolding around her. She wants to stay detached and not become emotional when caring for her patients. She tends to fade into the shadows, but is attentive to her patient’s physical needs, keeping her thoughts to herself. She felt that it was wrong that the family was allowing Patient A to suffer. Nursing Assistant 1 was confused and uncomfortable when Nurse 2 participated in the post mortem care and showed outward emotions by crying. In the two years since the death of Patient A, Nursing Assistant 1 has re-evaluated her goals and has decided to seek a career as a computer repair technician, a job that she will not have to deal with human emotions and care for patients she perceives as suffering.

The encounters that Nursing Assistant 2 had with Patient C were brief and the nurse was always in the room. She did not interact with the family, although she had a lot of empathy for them. The patient’s struggle to breathe and inability to speak because of the mask was troubling to Nursing Assistant 2 because she felt that she was suffering. Nursing Assistant 2 has a dual role at the hospital; she is monitor tech as well as a nursing assistant. Nursing Assistant 2 has never been in the room at the moment of death with a patient, but she watched Patient C die on the heart monitor, she said it gave her “a little chill” when the line went flat. She felt that the patient was “better off” because her suffering was over and was very glad that the family had been present.

Nursing Assistant 3 understands her role is to provide the patient comfort and address hygienic needs. She stated that she checked on the patient and family frequently. She had been
told in report that she should avoid moving the patient because she was so near death. When Patient D became soiled again, Nursing Assistant 3 made sure that the family wanted her to clean her up because she was afraid that she would not tolerate movement and she asked Nurse 4 for assistance. The nurse was not available to help Nursing Assistant 3 move the patient and when Patient D’s died as she turned her, Nursing Assistant 3 became very upset. She was already angry with Nurse 4 because she felt that the nurse had been neglecting the patient because she refused to help her twice. Nurse 4’s reaction to the patient’s death was interpreted by Nursing Assistant 3 that she had been wrong to move the patient and had caused the patient to die on their shift. She became very angry at Nurse 4 and since that night has tried to come to terms with her feelings but finds it very difficult to work with her because she feels that N4 is not giving good nursing care. Nursing Assistant 3 wondered if she had been “slack” in her role of nursing assistant and not been so attentive to Patient D, would she had died on her shift? The disharmony that ensued after the death of Patient D made Nursing Assistant 3 consider if she wanted to ever work with Nurse 4 again.

The nursing assistants were participant observers in the deaths of their patients. Nursing Assistant 1 and Nursing Assistant 2 were only minimally involved in the care of the patients and therefore did not interact much with the families. They both felt that their patients were suffering and that caused them distress. Nursing Assistant 3 was much more involved in the death of her patient because she had just completed care and was touching her as she died. She was already upset with her nurse because she was not giving care that Nursing Assistant 3 thought she should and her emotions erupted when she thought the nurse questioned her ability to properly care for her patients.
In summary, it is difficult to discern from the interviews whether these particular deaths affected the perceptions of the nursing assistants’ view of their role in caring for a patient at end of life or if it was other factors because they seemed to be comfortable with death. Nursing Assistant 1 is leaving her job as a nursing assistant to become a computer repair person and Nursing Assistant 2 is becoming a monitor tech. Nursing Assistant 3 had considered becoming a nurse but does not want to have the responsibilities and the paperwork a nurse has to deal with; she wants a job where she can interact and care for the elderly. She has dreams of owning a group home for seniors.

This concludes the section of this chapter of findings that addressed the second research question regarding the effect of the death on the role of the healthcare provider. The findings suggest that each participant found the experience to be meaningful to them and they will incorporate this in the future as they perform their role. In the following section the third research question is addressed.

**Differences in Perception of the Experience – Research Question #3**

In this section, the narratives of the participants are examined to address the third research question, *how did the perception of the experience differ among the different disciplines or roles of the healthcare providers?* This section discusses how members of each discipline view the other’s role in caring for the dying patient. The data in this study suggest that there were differences in the perceptions among the participants based upon their disciplines/roles as healthcare providers.

**The Nurses**

As with other hospitalized patients, the plan of care was directed by the physician, administered by the RN who was assisted by the nursing assistant. Each nurse saw her role to provide support to the family and comfort to the patient. The experienced nurses were
comfortable with death and being the patient advocate. Nurses provide treatments and medications based upon the physician’s orders. Nurses were more attuned to the emotional/spiritual aspects of the patient & family and saw their role to be a communicator as well as physical caregiver.

Nurse 1 and Nurse 2 are very religious and spiritual in their beliefs about death. They are both Catholic. They pray with their patients. They felt that the physicians had a more difficult time with death because they are reluctant to “give up” their fight against death. The entire focus of their narratives was to provide their patients with a good death, which is a death with comfort and the family present. They both provided the physical care of their patient. They viewed their role to be the patient advocate and got upset when they felt the patient had been wronged, Nurse 1 when a float was assigned to the patient and Nurse 2 when Physician 3 did not prepare the family for the patient’s death and he died alone. They both recognized the significance of death and wanted to be present at the time of death. Both nurses also mentioned that other staff did not share their views of providing presence at end of life. Nurse 2 actually told other nurses it was medication tasks that required her to spend so much time in the room.

Nurse 3 provided physical care with the assistance of Nursing Assistant 2 and communicated with the family and physicians. She did not administer pain medication until the daughter came in and gave permission because she was fearful that it would lower her blood pressure even more. She spoke with the physicians to clarify the plan of care when she found discrepancies. She coordinated the meeting with hospice and the daughter and stayed with the patient and family as the patient died. Nurse 3 sees her role as floor nurse to be much more involved with the family than when she was in intensive care and feels comfortable voicing her opinions regarding the plan of care with both the physicians and family. Nurse 3 was not as
emotionally invested as the other nurses; she noted the clinical cause of death to be a heart attack and did not speak of the spiritual aspects of end of life. She did say that the physicians were responsive to her requests and she felt the other staff supported her.

Nurse 4 saw her role as a nurse was to follow the physician orders so that her patients will improve. She hoped that Patient D would not die on her shift. When the patient died, Nurse 4 was uncomfortable with the “drama” and emotional displays. She was anxious and unsure of what to do. She felt that Nursing Assistant 3 had been unprofessional when “she yelled down the hall” when Patient D died. Nurse 4 feels that she must stay calm and unemotional to portray a sense of competence to her patients and that night she felt she did not. She found the whole experience to be distasteful. She spoke about how other nurses had to come into the room and examine the patient to confirm death. She was not comfortable with all aspects especially when she had to ask the family questions regarding disposition of the body immediately after the death.

The Physicians

Each physician saw his/her role was to direct the care of the patient in accordance with the patient/family wishes. At end of life frequently the patient is not able to voice their wishes and the physician relies on the input of the designated family decision maker to develop a plan of care. The clinical focus on disease processes and treatments was quite evident in the narrations by the physicians. Each described their patients by their disease process. They allowed the families autonomy to make decisions but they tended to rely on clinical judgments and not the spiritual realms of assessment.

Physician 1 and Physician 2 were experienced and were able to provide clear and concise direction for the end of life care and had the time to move the family to acceptance and permission to withdraw aggressive care. They saw the role of the nurse to be at the bedside to carry out the orders. They supported the nursing staff and expected them to report any issues
because nurses spent more time with the patients. They communicated clearly and frequently directly with the nurses who were caring for their patients. They also saw their role to be a mentor to the inexperienced physicians to help them provide excellent end of life care.

Physician 3 was definitely at a disadvantage in Patient A’s death due to his lack of experience. He lacked experience in American hospitals because he was trained in Puerto Rico. English is his second language and this made communication difficult at times due to his heavy Spanish accent which may have contributed to the miscommunication between him and Nurse 2. Patient A was one of his first experiences with a dying patient and the patient died within 18 hours of admission. Physician 3 was unable to recognize that death was imminent and support the palliative care plan. He focused on giving the family hope so that he could build trust with the son who had rejected the palliative care team’s assessment as not scientific because they cited the patient’s vision of angels as a sign of impending death. He believed he could provide empirical evidence with additional testing and time to either disprove or concur with the palliative care team’s prognosis. He did not share his plan with Nurse 2 which caused her to be unsure of her own assessment resulting in stress and anxiety it is not clear from P3’s narration why he did not communicate with Nurse 2, it could have been due to a lack of time or opportunity because they were both inexperienced and had a heavy workload.

The Nursing Assistants

The role of the nursing assistant is to assist the nurse in patient care, usually by providing hygiene and toileting. They normally are assigned to more patients than nurses but will spend most of their shift providing hands on care. All of the nursing assistants interviewed for this study wanted to provide comfort to the patient and they were distressed if they felt they could not as evidenced by Nursing Assistant 1 and Nursing Assistant 2 feeling that their patients were
suffering. Nursing Assistant 1 and Nursing Assistant 2 both did not interact with the family and observed the interactions of the nurses and physicians with the patient and family.

Nursing Assistant 3 did interact with the family. She was the principle provider of care to the patient because Nurse 4 was not available to help. Nurse 4 seemed reluctant to care for Patient D and this made Nursing Assistant 3 upset because she thought that Nurse 4 was not providing good patient care. This created conflict and increased emotions when the patient died. Nursing Assistant 3 felt insulted when Nurse 4 asked her why she turned the patient. Nurse 4 attempt at remaining cool and calm to demonstrate her competence had the opposite effect on Nursing Assistant 3; she thought Nurse 4 was uncaring and not providing good care.

This concludes the presentation of the findings of the third research question relating to how the participants view the roles of other healthcare providers at end of life. A patient’s death is a significant event in the day of healthcare provider fraught with many emotions which may cause disharmony. These emotions can become painful when they think that another healthcare provider is not providing appropriate care to the patient and family and can lead to conflict. This chapter continues with the summation of the findings and conclusions of this study.

**Findings Conclusions**

In this chapter I have discussed in great depth the findings in response to each research question. Each participant’s experience was unique and utilization of narrative analysis as the research method offered the opportunity to view the experience of a patient’s death through the eyes of each participant. The healthcare providers’ narratives provided evidence that the death of a patient in a general medical-surgical unit is a significant event and the study of the effects of the experiences on professional caregivers was warranted.

All of the participants in this study found the patient’s deaths to be meaningful experiences as evidenced by the emotions and thoughts that were expressed in the narratives. This implies
that whenever a death of a patient occurs; it can cause a mixture of emotions to emerge. There were feelings of frustration when there was discord or lack of harmony. Others felt sadness or empathy for the patient and family and sometimes relief that the patient’s suffering was over.

The participants felt their roles were to provide care and facilitate a “good death” for their patients. A good death was viewed by the participants as having several components that they sought to achieve, each differently as related to their role as a caregiver. Physicians focused on bringing the patient, family and other providers to a consensus in the plan of care while maintaining the patients’ right for autonomy and dignity. The nurses focused on providing holistic comfort care and communicating to the patient, family and the other providers. The nurses were more attuned to the patients’ and families’ spiritual/emotional needs. Experienced nurses were more comfortable with death and advocating for the patient. The nursing assistants provided intimate physical and hygienic care for patient comfort but did not interact extensively with the patients’ families and the physicians, instead their role was more like that of a participant observer to the events as they unfolded. The healthcare providers felt a sense of harmony when they perceived the patient had a “good death” and everyone shared mutual careplan goals, some providers were more successful than others in achieving harmony.

Some of the key factors that were identified by the analysis of the narratives which affected the providers’ abilities to facilitate harmony are (1) experience and knowledge of the provider, (2) openness of dialogue among providers, patients and families (3) attention to comfort of the patient, (4) providing support to the family (5) consensus in the plan of care among providers and family and (6) the patient not dying alone.

Each narrative with the exception of Patient B has elements of disharmony which contributed to moral distress in the healthcare providers. The disharmony was frequently
exacerbated by healthcare provider issues such as lack of experience and confidence with death and dying. Family disagreements and denial also created disharmony in the deaths of Patient A and Patient F.

The more experienced providers were comfortable in opening dialogue with the patient and family when the patient’s condition was trending downward and death was approaching. The inexperienced providers were unsure and doubted their feelings and assessments, especially if there was discordance or disharmony in the plan of care. A clear consensus in the careplan among the medical team, patient and family is an important factor that can determine whether the healthcare provider finds the experience to be positive. The data suggests that if there is indecision or nonacceptance of the careplan, the provider feels uncomfortable and may feel moral distress.

Lack of experience or knowledge will often cause healthcare providers to reflect and wonder if they had provided the right care, such as the nurses questioning whether medications administered hastened the death or the nursing assistant wondering if she hadn’t been so attentive and moved the patient, she might not had died during her shift. The physicians speculated if they had made the correct prognosis and learned to be careful to examine for evidence of impending death. Even the experienced healthcare providers wondered if they handled the situations appropriately.

Timing of the deaths also seemed to be an important factor that affected the harmony in these narratives. If the death was unexpected or happened very rapidly, before harmony and openness in dialogue about impending death could be created, the healthcare provider seemed to have more distress. For example, when the patient’s prognosis of impending death was ignored by the family, the inexperienced nurse felt great emotional distress and guilt when the patient
died suddenly. She felt that it was her fault that the patient died alone without his family at his bedside because she and the physician had not prepared the family. Two years later the same nurse showed tremendous growth when she cared for another dying patient and his wife in which death was discussed openly. She found the experience to be inspirational and lingered in the room hoping to be present at death. Another nurse was distressed that she was off duty when her patient died and thought it was wrong that a float nurse, who did not know the patient and family, was assigned to them even though everyone knew he was actively dying. A different nurse did not want her patient to die during her shift because she was afraid and felt insecure. She became very upset after the death, finding post mortem procedures and paperwork repulsive.

If the timing of death was not as rapid as expected, the healthcare provider may also experience distress. A physician discussed the conflict he had with himself and how the patient’s unexpected resiliency to death played with his emotions. He was comfortable with a palliative approach and encouraged the family to select this option of care because he felt that the patient was suffering from futile painful treatments. The family refused to withdraw aggressive treatment, causing the physician and other staff members much distress because the patient did not die as he expected. In the end, the patient died peacefully after life prolonging treatments were discontinued by the family, but this patient’s death made the physician question other times when he promoted palliative care with other patients.

Disharmony was also evident when there was conflict regarding roles of the healthcare providers. The providers were cognizant of other providers’ roles in caring for patients at end of life and volatile emotions erupted at the patient’s death when one provider did not feel another was providing appropriate care. Disharmony arose when perceptions of another’s actions were viewed as inappropriate, such as the excited and loud voice of the nursing assistant calling down
the hall to come in the middle of the night. This nurse found this to impinge on her ability to maintain a sense of calmness, an attribute she equated to competence and she felt that the family would think badly of her if she was not aware of the death. This nurse’s manner of coolness was interpreted by the nursing assistant as uncaring. Their misunderstandings of each other’s motives and view of roles escalated into anger when the patient died. In other narratives, conflict was not evident because each participant understood their role and that of the other healthcare providers’ role and a consensus was achieved in the plan of care.

The experience of caring for a dying patient did influence these healthcare providers’ view of their roles as professional caregivers. Some will choose to be in situations in the future where they can expect to interact and care for a dying patient and others are choosing to avoid dying patients. There was a general consensus that more education would be beneficial to help them improve their care as well as deal with the feelings that the death of a patient invokes.

The harmony/disharmony of these cases illustrates many implications about how the healthcare provider perceives the experience. When harmony is achieved in the careplan among the patient, family and staff, the experience is viewed as meaningful and good. Disharmony increases the stress and emotional burden of the healthcare provider and can have repercussions on the quality of care the patient receives. On the other hand, the data from this study suggests that when there is harmony because the provider feels supported by others, respected and a valuable team member, the event of a patient’s death is viewed as positive and meaningful. The implications of these findings and how they relate to the scholarly literature is discussed in detail in Chapter 5 of this dissertation.
CHAPTER 5
DISCUSSION

Introduction

As discussed in Chapter 1 there has been little previous research about healthcare providers’ experiences caring for a patient at end of life outside of intensive care or hospice settings. This study was designed to explore the experiences of nurses, physicians and nursing assistants who cared for a dying patient in the last 24 hours of their life in the medical surgical units of an acute care hospital. In the previous chapter (Chapter 4) key findings were presented from the analysis in a narrative format, retelling, the participants’ stories. In this chapter the findings of this study will be compared with other researchers’ published research of healthcare provider experiences in intensive care units and/or hospice, places where death is a common occurrence.

The Effect of Harmony/Disharmony on the Healthcare Provider’s Experience

Harmony\(^5\) versus disharmony was a central theme identified in the findings that influenced healthcare providers’ views of the experience. Harmony occurs when healthcare providers share congruent views or values (Bucknall & Thomas, 1997). Oberle and Hughes (2001, p. 707) stated that for high quality end of life care there must be “effective collaboration among doctors and nurses” and that each must appreciate the other’s point of view. When a healthcare provider does not understand another’s perspective or reasoning, it is stressful and can create a sense of disharmony. The data from this study suggest that healthcare providers will work to achieve a sense of harmony by collaborating with patients, families and other healthcare providers or choose to use defense mechanisms such as denial or distancing to cope with disharmony. The

\(^5\) Harmony is defined in *Merriam-Webster’s Collegiate Dictionary* (Mish, 2000; Venes, 2001, p. 530) as “pleasing or congruent arrangement of parts or correspondence or accord, internal calm or tranquility”.
findings presented in this dissertation also support the premise that there must be a sense of harmony among the healthcare providers, and patients and their families for healthcare providers to feel that the experiences were positive. Disharmony can impact the quality of care the patient receives at end of life and create a negative or stressful experience for the healthcare providers. Barriers to high quality end of life care such as societal attitudes, hospital systems, provider issues and patient/family conflicts can contribute to or create disharmony. In the following sections these barriers are discussed in the context of the findings and implications in this study.

**Societal Influences that Affect Harmony**

The death defying culture of America is supported in acute care hospitals due to the ability to prolong dying with advanced medical technology and many Americans are unfamiliar with palliative care (Yarbroff, Mandelblatt, & Ingham, 2004). Society’s view that people are victims of death and that death is a failure of medicine may contribute to physicians’ desires to please families. For example in this study, Patient A’s physician promised additional testing because the family did not accept that the patient was dying. These societal views may have also influenced the nurse’s perception that the physician and family were in denial. She felt the physician might have thought that death of a patient was failure. The physician was trying to facilitate harmony by providing the son hope the patient would get better. Neither the physician nor the son was familiar with palliative care concepts and the patient died before harmony among the providers and family could be achieved. Many “view the presence of hope in a dying patient as a kind of denial” (Connor, 1994, p. 165) but it is important not to confuse hope with denial, as in this case the physician was attempting to help the family have time to process information. Unfortunately the physician ran out of time because the patient died within hours of admission.

The acceptance of impending death and resulting harmony requires much effort by the healthcare providers. The physicians and nurses described facilitating the patients’ and families’
acceptance of a palliative care plan as a process that occurred over time. It could be speculated although harmony was present in the narratives about Patient B’s death; there most likely had been periods of disharmony prior to instituting palliative care in the last 24 hours of his life from the narratives of the physician and nurse. The physician described how the team had worked with the patient and family to change to the code status and accept palliative care for several weeks and the nurse spoke about her trepidation in meeting the wife because she heard in report that the wife was not happy with the care the patient had received and he had suffered so much.

Field and Cassel (1997) believe that patients can suffer during the medical model of care to cure disease and prolong life. The data from this study indicated that patients, their families and healthcare providers suffered as the patients endured treatments to prolong their lives. For example, Nurse 1 described how her patient had died in “inches” until everyone finally accepted that he would not recover. Physician 2 spoke about how his patient defied death repeatedly, surviving and suffering much longer than he thought possible.

Internal conflict and ambivalence about death is not unusual, it is normal in American society (Dubler, 2005). These feelings can cause disharmony as evidenced by the inexperienced nurses in this study. Nurse 2 felt incongruence and disharmony because “there were different sides telling different people different things”. She restructured her thoughts in an attempt to create harmony and decrease her stress by distancing herself and busying herself with the other patients. Distancing or withdrawal from a dying patient by staff members in an acute care hospital is not an uncommon mechanism to reduce stress (Vachon, 1986). In fact Nurse 4, the other inexperienced nurse, did the same thing when caring for Patient D. The distancing these nurses adopted actually contributed to creating more disharmony when the patients died. Nurse 4
had conflict with the nursing assistant and Nurse 2 felt guilty that Patient A died alone and she
had not been the patient’s advocate by sharing her thoughts that he was dying with the family.

Society’s attitudes are influenced and often reflected in the media that may portray dying
alone to be undesirable or a bad death (Yarbroff et al., 2004). Seale (2004) studied newspaper
stories about people who died alone and concluded that they were written to represent a
frightening fate resulting from personal or social failing. An example of this occurred when
Patient A died alone and Nurse 2 projected her own feelings of disharmony by assuming that the
family felt bad about leaving, but in fact they may have been distancing themselves as well.
Disharmony can evoke intense and painful emotions in healthcare providers that can be akin to
post traumatic stress as demonstrated by Nurse 2 as she cried frequently during the telling of her
story two years later.

Serious illnesses, such as chronic heart failure and respiratory failure, are often not
recognized as life-threatening illnesses that may “almost certainly cause eventual death” (Lynn,
1999, p.132). In this study, the families’ denial of the seriousness of the illnesses in Patient A
and Patient C contributed to the disharmony the nurses felt. The fact that these patients were not
admitted to hospice or an intensive care unit where the severity of an illness is acknowledged
could have also contributed to the incongruence or false belief that they were not sick enough to
be dying. Lynn (1999) and her colleagues from the SUPPORT study suggested that if there were
a greater acceptance of aging and death by American society, it would help facilitate the
acceptance of a caring (palliative) versus curing model in modern healthcare at end of life.

Organizational Structures that Affect Harmony

Many references in the end of life literature suggest the organizational structures of
hospitals can lead to increased stress and burnout of the healthcare providers (Badger, 2005;
Corely, 2002; Davidson et al., 2003; DelVecchio Good et al., 2004; Dodd-McCue & Tartaglia,
Organizational problems identified in this study that contributed to the disharmony felt by the healthcare providers included: issues with organizational hierarchy, staffing issues, and lack of protocols and training.

**Issues with organizational hierarchy**

Staff conflicts and disharmony may arise from organizational hierarchy (Bucknall & Thomas, 1997). Physicians direct the care of the patients and the nurse follows the orders and directs the nursing assistant. In the narratives of this study, it is interesting to note that generally the participants felt that their subordinate, that is doctor to nurse, nurse to nursing assistant, performed their role adequately. However, several participants were critical of their hierarchal superiors, Nursing Assistant 3 complained that the nurse did not give good nursing care and Nurse 2 was critical of the physician. Also Nurse 1 felt that the physicians had let Patient E “die in inches” by continuing futile care that caused great suffering for the patient, family and staff.

The implications of hierarchical dissatisfaction illustrated by the study participants’ stories are similar to the stress and compassion fatigue as described in. Buchnall & Thomas’ (1997) study of critical care nurses who were dissatisfied with treatment plans and “reported disharmony with the medical staff concerning decision-autonomy issues” (p. 236). Hierarchical conflicts can be intensified when the healthcare providers are already stressed by the disharmony as evidenced by the anger these providers in this study directed at their superiors. Vachon (1979) described how in hospice settings staff stress is sometimes expressed in staff conflict, “particularly in hostility toward the leader of the unit” (p. 137). In this dissertation study, Nurse 4 became very angry at the team leader when she assigned a “float” nurse to her dying patient.
Staffing issues

Staffing patterns. Issues with staffing patterns were most acutely felt by the nursing staff, because the patient to nurse ratio ranges from four to eight patients per nurse in the medical-surgical units, whereas an intensive care nurse typically is assigned 1-2 patients. Furthermore, float staff are often used on medical-surgical units resulting in a lack of continuity. Alternatively in hospice, The International Association for Hospice & Palliative Care (2009, p.10) suggests the inpatient hospice unit nursing staff should be permanent trained staff “of not less than one nurse to 1.5 patients throughout 24 hours” with at least 50% of the staff to be registered nurses to provide quality care. Nursing Assistants in the medical-surgical units also grapple with a high volume of patients. Participants in this study stated they could have up to 13 patients during a shift. Nursing Assistant 2 and Nursing Assistant 3, both stated that they had too many other patients to spend much time in the dying patient’s room. Vachon (1986) suggests that staff may feel anger and guilt when a dying patient and family expectations are not met. This was illustrated by Nurse 1 who was very upset and had feelings of anger at the team leader that a float nurse had been assigned to the patient when he died. This family had chosen to stay in the unit where they felt close to the staff, only to be assigned a stranger in the last hours of the patient’s life.

Disharmony from physician staffing patterns was also evident in the data. Physician 2 felt that changes in physician staffing (due to normal rotations) stalled the progress he had made with the family in moving them to acceptance of withdrawal of care. The patient was still lingering near death for several months receiving aggressive care until he rotated back on the service.

First year residents typically are responsible for the bulk of the work such as order writing and answering pages. Their patients may be spread out over many units so they often do not work as closely with the floor nurses as when a resident is assigned to the intensive care unit,
where they typically stay on the unit and spend more time interacting with the nursing staff. New physicians can feel much stress when dealing with unfamiliar situations and need much supervision in the beginning of their residency (Rios, Sanchez Gascon, Martinez Lage, & Guerrero, 2006). If Physician 3 had been more closely supervised or coached by his senior resident, he may not have suggested the unnecessary test or felt stressed and uncomfortable when he had to tell the family the test had been cancelled. He also missed a learning opportunity by not attending the family conference with palliative care because he was busy rounding on other patients. Perhaps if he had heard the palliative care consultant’s rationale for suggesting that the patient was imminently dying, he may have subsequently felt more comfortable supporting that plan of care to the family which in turn might have prevented the disharmony that Nurse 2 felt when she disagreed with his plans.

Staffing patterns can also affect the disharmony that patients and their families feel due to inconsistency of healthcare providers. Patients and families can feel abandonment by familiar staff when new providers are introduced in the last hours of life. For example, Patients A, B, C, D and E were new to the healthcare providers that cared for them in the last hours of their life due the providers either being off the previous day or new assignments.

**Staff Disagreements.** Disagreements or conflict among staff can create disharmony, especially between nursing and junior residents (Bucknall & Thomas, 1997). Often a nurse may view the appropriateness of medical care given by the amount of supervision a resident receives (Rice, Rady, Hamrick, Verheijde, & Pendergast, 2008). The nurse disagreed with what the physician told the family about Patient A’s condition and felt that palliative care’s prognosis was correct. However, her own inexperience and conditioning to follow physician orders made her doubt her own assessments. As a result, she did not advocate for the patient by challenging him
or calling his senior resident. She was angry at herself later when the patient died alone, and she felt guilty that she had not confronted Physician 3. The experience made her realize it is her role to be the patient’s advocate.

Another example of staff disagreement that led to disharmony among healthcare providers in the findings was that the nursing assistant and nurse disagreed on the care of Patient D. The nurse did not want to touch or move the patient for fear she would die on her shift and the nursing assistant thought that Nurse 4 was not giving proper care to the patient. The nursing assistant turned the patient to change the bedding to make her more comfortable at the family’s request. When the patient died while being turned, the nursing assistant became very angry at the nurse for questioning why she moved the patient to provide good patient care because she felt the nurse was blaming her for the patient’s death.

**Staff communication.** Poor communication among staff can significantly impact the quality of care of patients, especially at end of life (Yarbroff et al., 2004). There were deficiencies in communication during shift changes when Nurse 3 spoke about the misinformation she received in report regarding the code status of Patient C. It is not clear whether the departing nurse really understood the ramifications of the misinformation or if she too had been misinformed and just passed on misinformation because she too was unfamiliar with caring for a dying patient and did not question the code status. Hospital administration should encourage the healthcare providers to dialogue and discuss the patients so that a clear understanding is achieved before transfer of care and encourage the use of tools such as transfer mnemonic aids such as SBAR (Situation, background, assessment, recommendation) which can help improve the quality of the report (Riesenber, Leitzsch, & Little, 2009).
Protocols and training

Protocols within the organizational structure of the hospitals within this study were another source of disharmony. Lack of protocols can generate uncertainty and stress in the nurse (Dodd-McCue & Tartaglia, 2005). For example Nurse 4 felt inadequately prepared to care for a dying patient because the hospital end of life policies and protocols were not made available to her and had not been covered in her orientation.

Unit criteria and transfer protocols can become a barrier in good end of life care when there is a lack of continuity in care. When Patient B no longer met intensive care criteria he was transferred to the regular medical unit to receive palliative care with a different staff. Much of Nurse 2’s narrative was related to how she developed a rapport with the wife so that she could best care for the patient. Physician 1 spoke about how her team had followed the patient throughout his hospitalization because she recognized the need of the patient and wife to feel supported by the medical team. These two providers worked hard to maintain a sense of harmony for all by promoting good communication and presence so that the wife did not feel abandoned by the staff she was familiar with.

Staff training. Organizations must assure that the staff is adequately prepared to care for patients and families at end of life. End of life protocols, support and training for healthcare providers is necessary to reduce the uncertainty and stress an inexperienced provider may feel. If disharmony is persistent, stress and burnout of hospital employees can occur resulting in increased employee turnover and absenteeism (Goodman & Boss, 2002). Vachon (1979) suggests that new staff be given an extensive and thorough orientation to care for the dying patient. She also acknowledges that continued education for experienced staff is also necessary to reduce the staff’s stress and improve patient care and that hospices train their employees that “focus on the relationship between staff and patient is always on the process of dying” (p. 137).
Organizational culture. Disharmony among different levels of providers can be reduced with an organizational culture that promotes teamwork and mutual goal setting. All healthcare providers who are involved with caring for patients at end of life should be encouraged to participate in debriefing programs and team building exercises to prevent disfranchising or compassion fatigue and aide in grief resolution. This is important for nursing assistants because they provide intimate and physical care to the patients on a daily basis and may suffer with them (Anderson & Gaugler, 2006). For example, Nursing Assistant 2 “felt bad” because her patient had difficulty breathing. An example of disenfranchising of staff is Nursing Assistant 1; she did not share her thoughts or opinions, choosing instead to fade into the shadows to avoid conflict and emotions because she did not feel she was part of the team. Vachon (1979) writes that the use of interdisciplinary teams commonly utilized in the hospice setting can reduce staff stress because communication in enhanced and participants feel that responsibility is shared resulting in more effectual cooperation. This is an approach that might also reduce staff stress in the medical-surgical units and facilitate harmony as demonstrated in this study when the nurse, physicians, case manager and hospice team each contributed in the planning of the care of Patient C.

Healthcare Provider Issues that Affect Harmony

Formal educational preparation about end of life care is sorely needed as indicated by the inexperienced healthcare providers’ narratives that displayed great disharmony. Both of the inexperienced nurses in this study were graduates of the same associate degree program in nursing, where the focus is on preparing the acute care nurse. Neither felt their curriculum prepared them for the death of their first patient which is not surprising since education in skills, knowledge and attitudes of end of life care is commonly lacking in generic educational programs, i.e. medical and nursing schools (Jones, Garg, Bali, Yang, & Compton, 2006;
Wakefield, 2000; White, Coyne, & Patel, 2001). Casarett and colleagues (2002) identified that lack of education and training in end of life care was a deficiency. In 1965 Glaser and Strauss wrote that physicians and nurses were taught technical aspects of care but not how to communicate with the dying patient. Davidson and colleagues’ (2003) found that cardiorespiratory nurses lacked of knowledge to care for patients with non-malignant end stage disease and these two nurses in this study also lacked knowledge in caring for respiratory failure patients. This uncertainty and lack of knowledge caused them to feel disharmony.

Gaining experience and having ongoing opportunities for continuing education appear to help nurses and physicians cope with caring for a dying patient. Physician 3 reflected how the two years of experience he had gained since Patient A’s death has helped him in caring for other patients at end of life because he feels that he is quicker to recognize the signs of imminent death. He has also had the benefit of attending a monthly Palliative Medicine in-service where end of life education is provided for Family Practice physicians. Nurse 2 also showed much growth when she cared for Patient B two years later. She had returned to school to complete her bachelor’s degree in nursing and had written a paper on palliative care. Her increased knowledge and the palliative care plan contributed to the harmony that she felt caring for the patient and his wife.

The experienced providers in this study also stated that they would like more education in caring for patients at end of life. During the interviews several nurses and nursing assistants inquired about classes to help them feel more comfortable caring for the dying patient. Physician 2 expressed a desire to become credentialed in palliative medicine but due to family and financial commitments feels he cannot complete a fellowship at this time.
Healthcare providers bring with them their personal experiences with death and it can affect harmony. Several of the participants talked about how they imagined how they would want their loved one cared for to guide their actions. This role taking allowed the caregivers to be empathic to the families of the dying patients (Schell & Kayser-Jones, 2007). Two of the nurses made sure that the family was aware that pain medication might actually accelerate death before they administered the drug even though the delay caused the patients to experience more pain but the communication allowed everyone to be “on the same page” to restore harmony.

When a patient’s death “happened the way it should have”, healthcare providers in this study felt harmony. For example, Nurse 3 knew how badly her sister had felt after signing their mother’s paperwork to withdraw treatment so she felt that the family had been spared that anguish when the patient died before they could sign the paper work for hospice. This death was peaceful and not traumatic to the nurse, like so many other deaths she had witnessed when she worked in coronary care.

Spirituality is where some healthcare providers can find meaning in what they are doing (Winslow & Winslow, 2003). Spiritual care is a “significant component of end of life care” in the hospice/palliative care setting (Coyle, 2006, p. 36). Spiritual care was important to Nurse 1 and Nurse 2 because they saw prayer as an important part of their nursing care. The two are Catholic and have had personal experiences with “good” deaths of close family members in hospice care surrounded by the family. Both nurses felt that being present at time of death was important and they frequently prayed for and with their patients. Their spirituality and prayer support Smit’s (2005) findings that feelings of empathy and self-fulfillment can emerge when caring for the dying. Prayer as an intervention of spiritual care with patients and family is gaining renewed emphasis in nursing care (Winslow & Winslow, 2003). It is interesting to note
that prayer and spirituality was important to several participants who worked in the secular teaching hospital environment but spiritual care was not referenced by the nurses and nursing assistants who were employed by the Catholic hospital where prayers are said daily over the intercom.

Role taking or seeing the perspective of another person allows the caregiver to imagine what the patient or family feels (Schell & Kayser-Jones, 1999). Role taking can intensify the emotional distress or grief that can develop after a patient death. For example, Nurse 1 experienced profound grief after her patient died because she had grown very close to the patient and wife; she felt that they were “like family”. During the interview there was heaviness in her voice and she appeared to be suffering from compassion fatigue. As she told her story she seemed to find meaning from the experience and gained a better understanding of her emotions. A year later she stated although she still prayed for the patient and family, she did not feel overwhelmed with grief anymore and feels that this experience and others have made her a better nurse.

Compassion fatigue which has been likened to post traumatic stress can actually become healing or posttraumatic growth with changes in “interpersonal relationships, sense of self, and philosophy of life” (Kearney, Weininger, Vachon, Harrison, & Mount, 2009). Posttraumatic growth is the positive response to compassion fatigue and emotional trauma. There is evidence that Nurse 2 also experienced posttraumatic growth after the two years from the death of Patient A. In her description of caring for Patient B as she had developed a sense of self-awareness as evidenced by the ritual that she practices when she hears of a death by praying to her deceased father to greet and welcome the person to heaven. It would be interesting to re-interview Nurse 4
and Nursing Assistant 3 in two years to determine whether they too had posttraumatic growth from Patient D’s death as other participants have described.

**Patient and Family Conflicts that Affect Harmony**

Conflicts among patients and their families can be present long before the patient has become ill but may become exaggerated at end of life. A study by Winter and Park (2008) suggested that family discord can inhibit the preference of a palliative care plan and encourage life prolonging treatments. A family that has discord or conflict creates a sense of disharmony for the healthcare providers. It takes skillful healthcare providers to guide a patient and family though the dying process or as Quill (1996) so aptly phrased it, become a *midwife* to the dying. This process is the creation of harmony and healing in the face of death.

Providing futile and painful care to dying patients can be very distressing to healthcare providers (Badger, 2005). Harmony is not achieved when families maintain unrealistic treatment goals and do not accept that the patients’ illness will lead to death and healthcare providers feel the patient is suffering because the family has not grasped “the big picture” (Norton & Bowers, 2001, p.260). Physician 2 reflected that when there is disagreement about the careplan it can be mentally and emotionally exhaustive. The healthcare provider may perceive that the patient’s death was not a “good death” if the patient dies before resolution of family conflicts or the patient dies alone (Bailey et al., 2005; DelVecchio Good et al., 2004; Webb, 1997). Other components of a good death for patients include finishing personal business, reconnecting with family and forgiving and being forgiven (Norton & Bowers, 2001). When a healthcare provider feels that these tasks have not been accomplished there can be feelings of disharmony as when Nurse 2 described feelings of failure that she had not been a good nurse after her patient died.

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6 *Midwife* is defined in *Merriam-Webster’s Collegiate Dictionary* (Mish, 2000; Venes, 2001, p. 736) as to assist in producing or bringing forth or bringing about.
alone. The experience caused her to reevaluate her choice of profession. Other participants felt bad because they felt the family allowed the patient to suffer.

The decision to withdraw curative or life sustaining care is usually made in consultation with the family at end of life because the patient either disengaged or is often unable to communicate wishes (Dubler, 2005). Death in a hospital from a protracted illness is usually due to the late or non acceptance of palliation by the family and/or professional caregivers because they could not “give up” until death occurs or is very imminent. Patients, families and healthcare providers may suffer if harmony in the care plan of a dying patient is not achieved. In this study (with the exception of Patient A), harmony was achieved just hours or moments before death when the family had an opportunity to say gather and say goodbye resulting in what the providers viewed as a “good death”.

**Implications of Harmony/Disharmony at End of Life**

This study, although small, indicates that healthcare providers need to be better prepared to care for a dying patient so that everyone (the provider, patient and family) does not unnecessarily suffer. Initiatives to educate healthcare providers and society about palliative care that many hospices and end of life experts purport are important to reduce healthcare provider stress and to help achieve harmony and consensus at end of life (Alexander & Ritchie, 1990; Quill, 2002; Twohig & Byock, 2004; van Staa, Visser &vander Zouwe, 2000; White, Coyne & Patel, 2001; Williams, Wilson & Olsen, 2005). Better preparation and support to new healthcare providers will help them understand and deal with their emotions to facilitate harmony. End of life topics need to be added to basic curriculums of all healthcare education. Clinical experience in palliative care settings should be mandatory so providers can gain the technical skills and decrease their fear of death. Debriefing by trained facilitators should also be included in the curriculum to help the students to process and examine their thoughts and emotions. Activities
such as reflective journaling and writing or telling personal narratives can help the student be introspective to examine their own feelings about death.

New graduates should have guidance and support with formalized preceptor programs in which they work with a skilled professional who can transfer knowledge and skills. Hospitals need to formulate and communicate guidelines and protocols to follow and provide the support of other professionals to reduce uncertainty and stress which will help maintain harmony. This is critical because when there is disharmony and resulting moral distress, providers may leave their respective professions; compounding the shortages of nurses, may escalate due to staffing turnover (Pendry, 2007). Physicians and nursing assistants. Patient care quality will suffer and healthcare costs

**Contribution to science.**

This study was a beginning step to address the caregiving experiences of healthcare providers who cared for patients who died in non-critical care areas of a hospital. The findings were compared with other studies from critical care and hospice settings. The findings suggest that the experiences of providers on a medical-surgical unit are similar to those in intensive care or hospice units. However, because death of a patient is not as commonplace in medical-surgical units the providers are more likely to be unfamiliar with end of life care and protocols which can create stress and feelings of disharmony. Each provider’s experience was uniquely their own story.

Although limited to six patient deaths, this study contributes to the body of knowledge of the experiences of caring for patients at end of life in an acute care hospital general medical-surgical unit. It also supports Norton and Bower’s (2001) grounded theory, *Reconciling Decisions Near the End of Life*. Norton and Bowers examined home health, family practice, intensive care and oncology nurses’ and physicians’ perspectives of treatment choices at end of
life. They described strategies used by these providers to shift patient/family treatment choices from unrealistic or curative to accepting what they viewed as realistic palliative treatment. These strategies included “laying the groundwork” and “shifting the picture” which would result in the patient and family in “accepting a new picture” (pp. 264-267). This dissertation illustrates a similar process whereby, several nurses and physicians described their efforts to bring everyone to a consensus in the careplan and resulting harmony at the end of life.

**Limitations.**

As discussed in Chapter 3 (Methods), there are many limitations to this study. The study sample was small and homogeneous in that all of the deaths took place at the same hospital. However, there was a change in hospital ownership and philosophy during the data collection period. The data collection was a selective process, the participants once identified as meeting criteria, referred others for the study. The time between the event (death) and the interview ranged from less than a week to two years. What is remembered by the participants when they tell their stories may change with each telling and time may be a factor in what they choose to speak about. Therefore, the data captured is a “snapshot” in time that may change with each telling. Narrative analysis is an interpretive process and this researcher was new to the method so these findings are too are evolving as the researcher continues to consider other interpretations by readers of this dissertation.

**Conclusion: The Importance of Achieving Harmony**

In this chapter, I have discussed how the societal influences; organizational structure; personal characteristics of healthcare providers and views of patient and families influence the experiences of health care providers caring for patients at the end of life. The focus of this study was the interaction of the healthcare providers, patients and families. Disharmony is widespread in our healthcare system because conflict about end of life care “is endemic in American society”
as we continue to view death as our enemy and not a natural consequence of living (Dubler, 2005, p. 19). Close inspection of the stories of these participants showed their desire to achieve harmony with the patients, families and other healthcare providers. Skilled healthcare providers worked on achieving harmony which in turn promoted good patient care by channeling energy to help their patients have a peaceful death with family at the bedside. Those who were able to achieve harmony felt that the experience of caring for the patient at end of life was positive.

The death of a patient can be a painful experience, but when these providers examined their feelings during the telling of their narratives, they found meaning from the experience and several displayed post traumatic growth. It gave them a chance to reflect and reexamine their feelings and actions that day they cared for a dying patient and family. The experience will contribute to their personal growth and enable them to give better care for future patients and families at end of life. The stories in this study which had the greatest disharmony were with the inexperienced participants who experienced trauma to the psyche as evidenced by the tears that flowed as they told their stories. The tears were not bad; they were healing and helped the participants find meaning, inward peace and harmony as the ancient Roman philosopher, Lucius Annaeus Seneca stated:

Let the tears flow of their own accord: their flowing is not inconsistent with inward peace and harmony.
APPENDIX A
INTERVIEW GUIDE

Introduction:

Thank you for agreeing to talk with me. As you know, I am interested in finding out about your experiences when you cared for (name of patient)

- Tell me about yourself. Age, sex, experience, role.
- What is it like working here?
- Please start by telling the story of (patient’s name) illness and death
- What was the cause of death? What was it like? What were you thinking?
- How did you realize the patient was dying?
- What did you see as the patient was dying? How did you feel?
- I’d like to hear how the death affected you?
- Please take me through a sequence of your own reactions to the death.
- Looking back on your care of the patient, is there anything you would have done differently? What aspects, if any were disturbing to you?
- Describe how you felt about the care you provided. That of others?
- How do you see your role in caring for the patient? How do you see others?
# APPENDIX B
## SAMPLE COMPLETE TRANSCRIPT WITH NOTES

### Nurse 3

The following is the full transcript from the interview with Nurse 3 with notations:

<table>
<thead>
<tr>
<th>D- Thank you for agreeing to talk with me this evening. I’ve got some guideline questions to just get you talking and then just let you talk. Feel free to say what you need to say. I usually start by just asking you tell me a little about yourself, how long you have been a nurse.</th>
<th>15 years, critical care experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>N3- I’ve been a nurse, I think 15 years, close to that at least. I’ve spent most of my time post open heart surgery. You know, step-down unit. Um, I did a couple of years with critical care, I’ve done a couple of years in ED and most of the time just kept going out, started in open heart, step-down and went to critical care, went back to open heart for a couple of years, went to the ED for a couple of years, went back to open heart for a couple of years. Um and then switched over here when YYY took over XXX. I have been here a year since March.</td>
<td></td>
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<tr>
<td>D- so did you work at YYY prior for all of those 15 years?</td>
<td>Same employer, new location</td>
</tr>
<tr>
<td>N3- all those 15 years I have been with YYY.</td>
<td></td>
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<tr>
<td>D- Oh, ok. So what made you decide to come here.</td>
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<tr>
<td>N3- It’s a lot closer to my house and ….I wanted to you know, go to a different hospital but I didn’t want to leave YYYY really so it’s kinda like, hey really a transfer without having to totally disengage from YYY.</td>
<td></td>
</tr>
<tr>
<td>D- All of that seniority….</td>
<td></td>
</tr>
<tr>
<td>N3- There you go! [laugh]</td>
<td></td>
</tr>
<tr>
<td>D- So are you married?</td>
<td>Married, grand kids</td>
</tr>
<tr>
<td>N3- Yes</td>
<td></td>
</tr>
<tr>
<td>D- Have kids?</td>
<td></td>
</tr>
<tr>
<td>N3- Yes, grown and grandkids.</td>
<td></td>
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<tr>
<td>D- so you are a pretty experienced nurse, you worked in a lot of different areas. Have you had patients that have died on you?</td>
<td>Came to med-surg to get away from dying patients in critical care</td>
</tr>
<tr>
<td>N3- In critical care, quite often. That’s one of the reasons I left critical care! [laugh] It’s not my favorite part particularly I mean it’s, well it depends on the situation. But that’s a lot of end of life and especially back when I was doing it, we are looking back to the early 90’s. It was a lot of end stage but basically it was all that it was in critical care.</td>
<td></td>
</tr>
<tr>
<td>D- Did you do anything, you said you have been a nurse for 15 years, what did you do prior to that?</td>
<td>Military background</td>
</tr>
<tr>
<td>N3- I was in the military, but not as a nurse. Raisin kids and all</td>
<td></td>
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</tbody>
</table>
that stuff.

D-What’s it like working here?

N3- Here at XXX? …uh…. we are going through some challenges getting started, getting on our feet. So it's, but then there are changes going on at YYY also too. So between all of those changes plus, taking over a new place and everything, it’s been quite challenging. I think.

Feels hospital is challenging

D-What type of nursing degree do you have?

N3-Bachelors (went to community college and then local university for BSN).

BSN, & AA

D- Tell me about this patient that … you took care of, I guess it was about a week ago?

N3- Probably, I honestly don’t…I think it was a Thursday, cause I usually work Thursdays.

D-I think it was Monday.

N3- Yeah, it was a Monday.

D-It was an elderly lady?

N3- Right, but I had only had her the one day. So I just picked her up that morning. Hum and from what I was told and everything the family… so I’m not sure a whole lot of the clinical course while she was in, but she was elderly. Um. From what I had understood she had not progressed well during the course of the stay here. And had continued to deteriorate.

Only took care of patient on day of death.

D-What was her diagnosis?

N3- dududduddum…Let me try to remember. I don’t even remember. Basically it was lungs and I think, I don’t know if that was what primarily brought her in, but that’s what eventually … that was the major organ to fail. I think she kept developing aspiration pneumonias and things like that. And couldn’t fight it off. Um and just deteriorated till the point where they finally had talked to the family the night before and got… and I had been told it was a ‘do not resuscitate’ but actually it was a limited code. I’m not real good at all of the new terms, so I use the old… No compressions, no intubation. But they wanted vasoactives and all of that. So…

Had not done well, family had been talked to night before to make a limited code

D-So, …..what was it like when you got report and you heard all of this, what were your thoughts?

N3- They…..Report didn’t sound too horrible or scare me too much. They just said she wasn’t doing well and the family… Nobody talked about that there’s imminent death or ‘probably not going to make it’ you know that’s where you get a little more concerned. You know if somebody says, I think she’s going to be dead by noon, something like that, I’d been ..it would have made more of an impression but it didn’t really make an impression till I went in and assessed the patient, then you could see that she was not doing well.

Report didn’t talk about imminent death, but first assessment she knew it wouldn’t be long
<table>
<thead>
<tr>
<th>D-What did you see?</th>
<th>Responded to family, not to staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>N3-Respirations were labored and rapid. Which to me is one big signs that something is going on. She was not real responsive. She got more responsive with her family. So she was still responding…and I believe that the family had said that she had talked to them and said she had actually communicated. She was at points in the day woken up enough to actually communicate with them.</td>
<td>Responded to family, not to staff</td>
</tr>
<tr>
<td>D-So, she was on vasoactives?</td>
<td>BP was low</td>
</tr>
<tr>
<td>N3-No, not when I came in. When I came in they hadn’t told…I think they said that her pressures were like in the 90s, but when I came in it was 60.</td>
<td>Called for orders because she was a limited code.</td>
</tr>
<tr>
<td>D-Oh, my goodness!</td>
<td>Doctors were passing it off to each other</td>
</tr>
<tr>
<td>[laughter] N3- but she was able to respond with that still. And then so then I looked at the code paperwork and saw that she did need, that we were supposed to be using vasoactives and that so that’s when we called the doctors and …. They were pretty prompt and they came within an hour. A &amp;B were on call and got to see…… B was on-call while she came through with him. Actually the cardiologist was up there when I first, he had actually been in there before I did.</td>
<td>Called for orders because she was a limited code.</td>
</tr>
<tr>
<td>D- Who was the cardiologist?</td>
<td>Doctors were passing it off to each other</td>
</tr>
<tr>
<td>N3-Dr. C. So I came out and told him and that I had gotten a pressure of 68 and he gave me fluids. Told me to call the renal doctor. Which we did and he just ..What did he tell me to do? He gave me an order right over there on the phone. He was aware of what was going on. He gave me…Albumin which made sense because she was 3rd spacing.</td>
<td>Doctors were passing it off to each other</td>
</tr>
<tr>
<td>D-Did the fluids help?</td>
<td></td>
</tr>
<tr>
<td>N3-No…</td>
<td></td>
</tr>
<tr>
<td>D-Did they make her more short of breath?</td>
<td></td>
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<tr>
<td>N3- I don’t know if they did either. Um but they weren’t … she responded one time, but not immediately after half of the bag went in. I got one pressure that went to the 120s but within 15 minutes it was back down to the 60s. And I got a few 90s.</td>
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<tr>
<td>D-When did you realize this patient was dying?</td>
<td></td>
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<tr>
<td>N3-Well, I kinda considered that she was dying when I first assessed her. [laugh] Now would I have put money on how long it would take, no. An actually even up to the very end…. She died rather quickly. I think she ….I guess you read the whole scenario.</td>
<td></td>
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<tr>
<td>D- Well no, I actually have not looked at the chart or …</td>
<td></td>
</tr>
<tr>
<td>N3- Well Ok..</td>
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</tr>
<tr>
<td>D-I’m really…PCT told me what she saw and I’m really just wondering what your experience was and how this was</td>
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</table>
compared to other patients you’ve cared for that were dying and what...

| N3-You have to remember most of my taking care of patients was long ago and in the days before hospice really and where doctors got comfortable with letting people die. So I’m basing my opinion, in so in compared to that…which I consider nightmares and horror and horrific and … I consider more suffering inflicted on mankind by loved ones and people trying to do good intentions than half of the stuff you hear about … torture. Yes, more true suffering, but that’s my opinion, but… so … nothing that happened this day was particularly upsetting to me. I’m a lot more comfortable with the way this patient was … the care this patient received. So because when the doctors came in you know the cardiologist did his little bit, but he said, I’m really not …basically not in so many words, but he told me to call renal and to call the attending. Most of what I got from the doctors, they let me know in the way that we are not looking to be very aggressive here. We’ve talked to the family um… and the night nurse did tell me that. He saw thorough the night the family holding some conversations with the patient and talking like they were finally, that they were accepting that it was time to start saying goodbye. So I kinda had that frame of mind that everybody kinda getting on page. It’s new to them and they are still processing but they’re there’s really nobody fighting. What everybody sees. When Dr. L came up, which was shortly after the pressures and we decided to start on vasoactives, but we told them we couldn’t run dopamine higher than 5 mics on the floor and do you want her transferred to ICU and Dr. D was in with him and he looked at her and said, ‘She’s dying’. So they decide and I….. to keep her here and run the dopamine as high as you can but ….. you know…………we were here. It made sense. The granddaughter was able … to come in after that and she was able to talk with her. She saw her grandson that she seemed to recognize. But she really wasn’t verbal. She could nod her head… and uh.. she was in pain, she did say that. I was too afraid to give any pain medication at that point because I had no blood pressure and I didn’t have no clear directives. Dr. L had said to consult hospice. They had not come up at that point. …… And then once they got there ….. | Previous deaths in ICU she considered torture….More suffering. This death didn’t upset her |
| | Family was saying goodbyes |
| | Started dopamine, but did not transfer to ICU |
| | She’s dying |
| | Afraid to give pain medication due to BP and no clear directives |
| D- So hospice came in and evaluated.. |
| N3-yes they did. |
| D-Did they make her a palliative bed at that point? |
| N3-She said, she wanted to she…what were their … they had to talk to the family. They had to get the family to agree. And that was probably the major holdup. Because the granddaughter had said she was calling the daughter when she had left at 10 in Hospice referred. Daughter didn’t come as expected…3 hours |

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the morning. ‘Denise is coming up, Denise is coming up.’ But that’s …. I don’t know if she actually had the legal power of attorney but the one the family, basically it was the one that the family agreed to make the decision maker. And so we were kinda waiting for Denise and hospice knew that and they had called the home and been told that she was on her way to the hospital. For some reason it took her 3 or more hours it seems to me from what I remember. She didn’t come as quickly as I thought. So the hospice nurse was up here, did her whole evaluation she told me that she was recommending that a palliative bed… She was only Nubane for pain and that she would switch her to Dilaudid, she would recommend that they switch her to Dilaudid for her pain and get her pain controlled. They were just waiting for the family to talk to. Then she even had time, she had another patient and she went and did another patient and all of that and son came up and a grandson and they spent some time with her. And this whole time her pressure is stayed mostly in the 60s -70s-80s. I’m trying to remember if we gave any other treatments in between. What else

<table>
<thead>
<tr>
<th>D-What did you do as far as caring for her at that time?</th>
<th>Palliative orders were pending until daughter came</th>
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<tbody>
<tr>
<td>N3- Basically, just uh…….just monitoring her, trying to position ….couldn’t really give pain meds , so tried to reposition her and help her that way…Um…. She was mostly out of it. She only became responsive when her family actually tried to…..She was on a bipap machine this whole time. So when …. Her sats were holding…. She couldn’t really communicate because of that.. it was only when they were actually even pull the mask away and tried to look her right in the eye and talk to her they were able to get communication from her.</td>
<td>When daughter came, hospice was busy</td>
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<tr>
<th>D-What was her pain level? Were you able to assess that?</th>
<th>Tried comfort measures</th>
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</table>
| N3-No, she wasn’t… like I said she did was nod her head. But she did when um when the family came through and it was just a matter of getting Denise and the hospice nurse together, took 10-15 minutes to locate her in the hospital. But in the meantime, she had talked to her mother and had said she was in pain so I decided at that point that we were close enough to getting a hospice order and that kinda stuff, I gave the Nubane….I only gave half of the Nubane which was like 0.5. She had said to Denise that she was hurting and I explained to the family, I said her blood pressure the way it is, the pain medicine is likely to affect that…… and it could possibly make it worse.. Do you understand that? It is a decision we can make and they said, just give her pain medicine. So we did, we started slow and gave that and she bottomed out within 15 minutes and so all of that happened all at once. Denise and the social worker got together and they were going to give the

<table>
<thead>
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<th>Decided to give Nubane only half</th>
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<td>15 minutes later patient had MI</td>
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</table>
talk...As they were going off to give the talk, I was giving the pain medicine, by the time they got back, I had no pressure...I never could hear one, only could get an automatic and by then the automatic wouldn’t pick up the pressure.... And then were acute changes on the telemetry. She had a MI. And that’s….

So the family came back, they were ready they kinda knew, they had had a chance to talk to hospice. They knew what it meant, what they were doing. It made the decision, yes they were going to do that. They didn’t really get a chance to sign, but they gave their verbal and hospice said, get the doctor on the phone and get the palliative bed order. So I had to call and I had to ask if I could have the palliative bed and they wanted the bipap removed so they could talk to her and he gave me those orders on the phone right away. By the time we got the bipap off, uh each of them, I think there was three at the bedside were able to kiss her and they knew we were losing her at any point.

<table>
<thead>
<tr>
<th>D-So it went pretty quick…</th>
<th>Got palliative bed order and orders, patient died</th>
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<tbody>
<tr>
<td>N3-Very quick… within 20 minutes. I think not traumatic because to me it almost worked the best way it could, they kinda had made the decision, but they didn’t really have to go through with it...One of them said, ‘she kinda took the decision out of our hands, didn’t she?’ And they said, yeah she did. The daughter seemed to be relieved to hear that. You know I think that’s the hard part…. I’m killing somebody... No matter how you explain it to them, they know it’s not… It’s still hard to …. So they didn’t really have to in my opinion..</td>
<td></td>
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<tr>
<td>Patient’s quick demise took decisions making away for family. They found comfort in it.</td>
<td></td>
</tr>
<tr>
<td>D-How did you feel about when giving the medication, knowing that ….</td>
<td></td>
</tr>
<tr>
<td>N3-I didn’t think it would be that quick… And I didn’t realize....And I don’t think…. I still don’t know if that medicine caused her to have an MI, I think…. She had the ST elevation.</td>
<td></td>
</tr>
<tr>
<td>D-Sometimes I think when you get them out of pain… then they let go....Sometimes pain can keep them here.</td>
<td></td>
</tr>
<tr>
<td>N3-Could be what happened. Although, 0.5 of Nuban ….but if it lowered the pressure … it could be.... But uh, I really thought it would be a respiratory and it would be all night… I thought there was more family coming and it would be all night. My projection was 10-15 people up here saying goodbye, throughout the evening, probably be a respiratory thing, and that would just gradually .....Though the night…. Occur.</td>
<td></td>
</tr>
<tr>
<td>D-But it happened during the day….</td>
<td></td>
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<tr>
<td>N3- I was still on, it was 4-5 o’clock. 5 o’clock I think we declared. So.</td>
<td></td>
</tr>
<tr>
<td>D-Have you thought about this death any since it happened?</td>
<td></td>
</tr>
<tr>
<td>N3-Actually I’m not upset about this one, so no I haven’t gone</td>
<td>This death brought back</td>
</tr>
</tbody>
</table>
home and tormented. You know, I’ve thought about it and it brings back more horror memories from years ago….Watching people swell up with fluids seeping out all over and still having to………..

| bad memories |

| D-How many other patients did you have to take care of that day? |
| N3-Probably…..it was not a bad day….I think I had 4 total. I might have had 5 at one point, I don’t remember |

| Not a too busy day |

| D-It’s busy. |
| N3-Five- that’s busy. But it wasn’t a horrible day. I wasn’t screaming and[laugh] it was busy enough, there wasn’t no time off…. |

| Charting keeps her away from giving care to her patients |

| D- how does that compare, I mean you’ve had horrible times in ICU but you only had one or two patients when you were in ICU, now you had 4 or 5 patients when you had this patient dying. Does it make a difference to you? |
| N3-yeah! It’s not the taking care of the other patients, it’s the charting..  The charting that takes… the other five… it just seems to me it’s easier for me to get in a room and take care of somebody, do what I’ve got to do and get out. But when I have to sit down and chart and all of the time.. And it’s ….charting is not my favorite thing. [laugh] I thought the computer would be better and to me it’s worse. Ten times worse. |

| Charting keeps her away from giving care to her patients |

| D-And we know you are going all of the place with the computer, |
| N3- And you have to compartmentalize everything. So just the way the notes … the PIE… You compartmentalize everything….oh don’t talk about respirations here cause we’re doing you know…..safety. Gotta save that when I get to respiratory. I don’t think that way. I hate charting, but you leave out the big picture, you leave out because you are so focused on the little picky details. And you don’t really give a ? But that’s a whole different subject, so we won’t get off on that. |

| Charting keeps her away from giving care to her patients |

| N3-I’m trying to remember the day, I don’t think I had any horrible patients, so it was easy enough to take care of and meet their needs. It wasn’t a bad day like I said. I didn’t have any major complaints or issues or problems…. |

| Charting keeps her away from giving care to her patients |

| D- So did you spend a lot of time in the room with them? |
| N3- Um…..well, I don’t know what you consider a lot? I’m sure I spent more time there than any other patient. I did get a cath lab patient, I remember, I picked that in the afternoon. It was a cath lab guy who came back. So I only had to leave.. I spent about an hour more over there with him because you have post cath vital signs and all that stuff. But for the rest of the time I was able to spend most …a lot of time in that room. Although…..I tried to give the family you know when the |

| Spent a lot of time in patient’s room |
family was in there I tried …I didn’t want to hover around. And she wasn’t changing. Actually up until the MI, she was ….The respirations still stayed, they never went up above 28, they stayed in the 20s the whole time. They didn’t really get more labored. Uh, she had stopped, shut down, no urine. …..They only have me give… I only gave, I can’t remember if it was a 250 or 500 bolus. I think it was a 500 bolus, but it wasn’t like we were running continuous fluids. I gave the bolus and the albumin and pumped the dopamine. So it wasn’t like I was pouring fluids into her or anything like that. Her belly had started to distend and when she …She probably would have benefited medically from a NG tube, but uh…..I think she was better off that we didn’t do that.

D-Do you think that you did too much or too little considering…..

N3-I wish I had medicated her for pain, but no considering what happened with just the …..And looking in hindsight I don’t think that there was a whole lot more….You’d say I wish the family would have had maybe more time to know that they could have been in there. If maybe they would have known, maybe they would have come. I’m sure probably some of them get up there and wished they had. But you know the doctor, Dr. D knew …..she knew… Because Dr. B talked with her about, should I send her to ICU and put more in and she’s like ……she died…. So they knew it but they know that she was going to be dead by 5 o’clock that afternoon. That we should have called everybody in. I don’t see where the hospice knew right away… I’ll agree that all of the medical……..I think that the family probably didn’t realize that , I don’t know. Because we couldn’t have said, If we had told them that she will be dead by five, make up your mind… [laugh]……That doesn’t work! [laugh] So looking back, I don’t honestly know …..she……realistically could have been……And I think that it’s good and I’m happy they were able… I do know that at least they made some….when she told them that….because we explained to the daughter and son it will probably cause the blood pressure to reduce and it may cause the ……it may make her death more imminent and they talked, the daughter talked… the daughter lifted her mask and said, ‘Mom, do you want the pain medicine?’ And so she said…….I think that’s the best thing the family can get, is when they don’t have to make that decision. This is when the patient is able to make as much of the decision for themselves to take that guilt off. And uh I think that can be comfortable there. They did what she asked for. They were… the family was pretty reasonable. There wasn’t a lot of drama.
<table>
<thead>
<tr>
<th>D</th>
<th>It happened pretty quickly from what I understand that she came in and it was just a very quick downslide. How old was she?</th>
</tr>
</thead>
<tbody>
<tr>
<td>N3</td>
<td>In her 80s. Yeah definitely. I’m thinking, I know she was over 80, whether she was 82 or 92, I can’t remember. Definitely not 50 or 60.</td>
</tr>
<tr>
<td>D</td>
<td>How do you feel; do you think hospice should have been involved sooner?</td>
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<tr>
<td>N3</td>
<td>I’m thinking could have probably… yeah, it would have been better in the long run if the family would have had a little more time. Maybe it would have been better for them but …..And I don’t know because I didn’t take care of her earlier. So it’s probably not fair for me to say, I can only assume that I think the medical team went more with the family’s pace. I was given the impression that the family …see even on that Friday night when they surely probably approached them with hospice, they didn’t automatically go to a ‘do not resuscitate’, the family chose limited. So in my mind that means the family was probably the hold up. They were not ready to say, ‘let’s this happen’.</td>
</tr>
<tr>
<td>D</td>
<td>Did you see Dr. X’s interactions that morning with her family?</td>
</tr>
<tr>
<td>N3</td>
<td>No, The papers had been signed the night before. And the family didn’t change until they went and talked with the hospice nurse. It was within the hour of her death. So {unintelligible} I wasn’t involved in all of the decision making, it just seems to me by what I saw that day, that the family wasn’t ready to process. I can’t remember if the night nurse told me that there was one of the children that disagreed with the rest or something like that. But I didn’t see any of that drama or anything going on amongst them.</td>
</tr>
<tr>
<td>D</td>
<td>How did the other staff caring for the patient, how did they do? Did you feel supported by the other staff?</td>
</tr>
<tr>
<td>N3</td>
<td>M was the team leader for the day, for both floors, and she’s one that I have the most respect for personally. She was very supportive. Didn’t really need a lot. You know there wasn’t …cause of being able to hear Dr. X &amp; Dr. Y and all , everybody seemed to be in agreement. I didn’t have somebody who seemed, ‘wait, wait,’ Everybody seemed to be on the same page. This is end of life, but we’re not all excited about doing something heroic here. Let’s just …the course…in the kindest way possible. That’s the idea, so I was never really super tense. I didn’t really ever go ask for a lot of help for everything. I think somebody when they saw the EKG changes they sent M running over to see if we were OK. But there was really not a</td>
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Thought that maybe the family wasn’t ready  
Family changed after talking with Hospice  
Felt very supported by team leader
<table>
<thead>
<tr>
<th><strong>D</strong></th>
<th><strong>N3</strong></th>
<th><strong>PCT did physical duties</strong></th>
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<tbody>
<tr>
<td>You have some help from the PCT in doing some of the physical care and.</td>
<td>Right cleaning and turning and things like that.</td>
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<td></td>
<td>She talked about a rectal tube.</td>
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<td></td>
<td>There was a rectal bag. And the night nurse had noted that the…that was surprising. The urine had cut down but she was still stooling. You know I just had her help me keep it empty from time to time. But you were able to, I don’t think it encumbered the family too much or anything like that. You were able to keep.</td>
<td></td>
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<tr>
<td>Did you talk to the family much?</td>
<td>The granddaughter….</td>
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<td></td>
<td>She was by herself…</td>
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<td></td>
<td>with just her little boy. I think he was like 16 months old. What did I tell her? I mean we didn’t go into any kind of personal or other than just how old her little one was. Um basically I let her know that we weren’t having good blood pressure and we were going to have to start…. She knew we were starting the drugs to try and help….That she wasn’t responding very well…to the therapies, but um I don’t know, I don’t think, cause she left. She said she talked to? and whoever…was coming up and they said she would be up. So I don’t think that imminent or anything at …</td>
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<tr>
<td>So how do you see your role as a nurse when a patient is dying? What’s your goal?</td>
<td>My goal? Is to help the family. Help them find some level of comfort, to make it as least traumatic as possible. It’s a natural part of…I can’t believe that God didn’t intend for people to die. Or there wouldn’t be set up the way it is that we die. We are supposed to die. Especially when you have somebody that is 82 or 92 or whatever they are supposed to die.</td>
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<tr>
<td></td>
<td>To help family find comfort</td>
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<tr>
<td></td>
<td>Believes that death is natural</td>
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<tr>
<td>What’s your religion?</td>
<td>I am a Unitarian. So to me the hardest lies in the family. The family that has to live or has the trouble, that has to process the death. It is usually what my experience is the one that has almost checked out mentally, usually; she was one of the most alert. At least we were able to get her to shake her head. Most people are checked out way before in my experience. Because I’m not used to trauma, you know, I was talking to them.</td>
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<td></td>
<td>Feels for the family</td>
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<tr>
<td>If your patient is near death and they are alone, do you change anything with what you do?</td>
<td>I know I remember in CCU, when I was a night nurse in CCU, would I change anything? Yeah, probably back then, you used to spend more time. I remember wondering, death being</td>
<td></td>
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<td></td>
<td>Spent more time with patients when near death in ICU</td>
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</table>
new.....looking at them and all the fuss, what is going on, what’s right, what’s wrong? I think I did a lot more soul searching back then. Out on the floor, my experience is usually is dealing more with families and I have become more comfortable talking to the family about you know, you can make decisions about how much care, whether they need to be stuck everyday....and it used to be very …that’s not my place to say anything. I shouldn’t say anything. But I can even remember they were not that?????? the cancer patients and all that. The family usually came back and appreciated that I told them what they should do at all, but at certain points sometimes they don’t have to know all of the labs every day, it’s not going to change the way. This is something that… these are the little decisions that you can make. It’s not just a decision of do we pull the plug? Or do we do everything. It doesn’t have to be all are nothing. There’s many, many stages so and most of the time they come back thankful to know that stuff. At least they’ve always come back and thanked me a lot for talking and taking the time to sit down and talk with them. So that is usually one of the bigger roles, you don’t get much response from the patient, it’s not like one of those surgery patients that come back and tell you, oh yeah, that was important that you did that or and that I like you know, that made a difference. You never know what you’ve done with the patient. They never come back and tell {laugh}

On med-surg spends more time with the family

Doesn’t get the feedback like with surgical patients who come back well.

Doesn’t get the feedback like with surgical patients who come back well.

Wants to know everyone is on the same page

There was time to say
was time to say goodbye. Maybe a little more time with it, but all said in total, but I do think that it is better that, you know I think it was Hospice was recommending palliative bed, take the bipap off. That’s what they were going to recommend and then medicate. So in my mind they knew watching the respiratory distress, in more of the respiratory distress, it gets a little harder to watch sometimes. Thank God at least on the floor you don’t have the monitors in the room, that used to be a little hard…watching it and the family would be watching it. [laugh] Yeah!

D-[laugh] I know exactly what your mean!

N3-Um, so I think it was …. I mean I have a sister that they, my father and my sister had to sign, this was back in ’88 for my mother who was on dialysis, in a coma and uh basically they had to sign to take the dialysis off. My sister went through two years of therapy and two years later and came to me and I was living out of state and not at home when this happened. ‘Oh, I have to apologize for killing your mother’. What are you talking about? Well, and she referred to it as the day she killed her mother and she really had a hard time dealing with and they all knew that she was dying. We all knew she was dying for months, I don’t think we killed her! Well she said, I signed that paper.

D-Signing that paper is a hard thing to do.

N3-It is a hard thing to do. My father wouldn’t sign it unless my sister signed it with him and it was hard for both so….and I think that ….that is one of the hardest things to do for your family.

D-I think St. Vincent’s has something that is good though, Allow Natural Death versus DNR and that is definitely easier to talk to the family about and when you are talking about the options to …

N3-So I need to get up to speed better on that. I have heard that they have changed the terminology, but I hadn’t really gotten up to speed on it. But this is the first time in all fairness, I ever had to deal with it since I was in an ICU or since leaving ….

Definitely since they’ve changed the terminology. I did have some cancer back when I was on 2E, maybe two or three of those ….but that was basically…they didn’t allow them there, they didn’t stay there till the end. But you were there when they got their original first diagnosis. You knew it was terminal….

D-Do you think it is harder for people to deal with a respiratory distress death versus a cancer death? The acceptance of families?

N3-Um...The difference of which is harder to watch. The respiratory is I think is harder to watch. …..I can only

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<td>Respiratory distress is hard to watch. Likes that there aren’t monitors in the room to watch.</td>
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<td>Talked about how hard it was for her sister to sign papers to d/c dialysis for her mother, she felt she killed her mother.</td>
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<td>First death since ICU days</td>
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<tr>
<td>D-Do you think it is harder for people to deal with a respiratory distress death versus a cancer death? The acceptance of families?</td>
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<tr>
<td>N3-Um...The difference of which is harder to watch. The respiratory is I think is harder to watch. …..I can only</td>
<td>Diagnosis of respiratory distress harder to predict</td>
</tr>
</tbody>
</table>
speculate, I think they understand a lot more with cancer, because they understand that cancer kills. A lot of them have more vagueness about respiratory you know, they’re not so convinced that it has to kill.

D- And you go just like this [motioned a wave up & down]

N3- Exactly, exactly you know bottom out, the patient’s been at death’s door four times and recovered and come back, half the time they think, oh yeah, I know you’re all telling me it’s bad, but I know she’s going to be ok still, just like the last four times. Yeah, stuff like that, it’s hard to accept.

D- I worked at Mayo to help to set up the palliative care consult service and that’s really how I got this interest in talking with nurses because I dealt with a lot of giving the nurses a lot of support and giving the family needing, having the family conference, before they could go to hospice, because Hospice is like a bad word and with palliative care where you do treatments or supportive care, but your goal is to alleviate symptoms versus cure, it’s true medical care, but it it’s a little bit easier to deal with but so many times by the time we would get the patient for referral to palliative care they should have been a hospice two or three weeks before, if not sooner.

N3- I think you are right, that’s probably what could have been the case here. I wasn’t involved in all of that earlier. That interesting and that is where we need to be going. But the nurses need a lot more education too, cause I’m not comfortable…

D- I will have to come back and do a class for yawl.

N3- That would be wonderful! That would be wonderful. It is much easier when you are more comfortable with that it is okay to say what you want to say. You are supposed to be pushing the hospital’s agenda, not my agenda, you know.

D- You believe you want to do what is right for the patient, though

N3- The patient and family above all else. I still hopefully assume that’s the hospital wants too [laugh].

D- Actually the hospitals make their money the first three days of admission, after that they start to lose money and because most payments, especially Medicare is based upon the diagnosis, so you get a lump sum and if you can change them into a hospice or palliative bed, you start getting money again.

N3- I didn’t know any of that. I don’t know any of that stuff.

D- So that’s why having a palliative care service can actually save money and help hospitals be more profitable by decreasing the length of stay. You don’t want patients to stay in the hospital more than three to four days because after that you start losing money. Because it becomes a freebee. So that’s why it
is important to get all of the test done earlier on in the admission and if like they need to have EGD, so you get them prepped and ready so that you don’t have wait and that they can go the next day.

N3-that’s a lot of major challenges I see.
Nurse 3

The following section displays the parsed and re-transcribed versions of the transcript and poetic structure analysis:

<table>
<thead>
<tr>
<th>Retranscribed Version of Story of Nurse 3</th>
<th>Analysis of Poetic Structure of Story of Nurse 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>001</strong> I’m trying to remember the day,</td>
<td>FRAME STANZA 1</td>
</tr>
<tr>
<td><strong>002</strong> it was a Monday.</td>
<td><strong>001</strong> I’m trying to remember the day,</td>
</tr>
<tr>
<td><strong>003</strong> I don’t think I had any horrible patients,</td>
<td><strong>002</strong> it was a Monday.</td>
</tr>
<tr>
<td><strong>004</strong> so it was easy enough to take care of</td>
<td><strong>003</strong> I don’t think I had any horrible patients,</td>
</tr>
<tr>
<td><strong>005</strong> and meet their needs.</td>
<td><strong>004</strong> so it was easy enough to take care of</td>
</tr>
<tr>
<td><strong>006</strong> But it wasn’t a horrible day.</td>
<td><strong>005</strong> and meet their needs.</td>
</tr>
<tr>
<td><strong>007</strong> I’m sure I spent more time there than any other patient.</td>
<td>STANZA 2 (Comparing the day to others)</td>
</tr>
<tr>
<td><strong>008</strong> I didn’t have any major complaints or issues or problems….</td>
<td><strong>006</strong> But it wasn’t a horrible day.</td>
</tr>
<tr>
<td><strong>009</strong> I wasn’t screaming</td>
<td><strong>007</strong> I’m sure I spent more time there than any other patient.</td>
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<tr>
<td><strong>010</strong> and [laugh] it was busy enough,</td>
<td><strong>008</strong> I didn’t have any major complaints or issues or problems….</td>
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<tr>
<td><strong>011</strong> there wasn’t no time off….</td>
<td><strong>009</strong> I wasn’t screaming</td>
</tr>
<tr>
<td><strong>012</strong> It wasn’t a bad day like I said.</td>
<td><strong>010</strong> and [laugh] it was busy enough,</td>
</tr>
<tr>
<td><strong>013</strong> I had only had her the one day.</td>
<td><strong>011</strong> there wasn’t no time off….</td>
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<tr>
<td><strong>014</strong> So I just picked her up that morning.</td>
<td><strong>012</strong> It wasn’t a bad day like I said.</td>
</tr>
<tr>
<td><strong>015</strong> From what I had understood</td>
<td>**STANZA 3 (Introduces the Patient)</td>
</tr>
<tr>
<td><strong>016</strong> she had not progressed well during the course of the stay here</td>
<td><strong>013</strong> I had only had her the one day.</td>
</tr>
<tr>
<td><strong>017</strong> and had continued to deteriorate till the point</td>
<td><strong>014</strong> So I just picked her up that morning.</td>
</tr>
<tr>
<td><strong>018</strong> where they finally had talked to the family the night before</td>
<td><strong>015</strong> From what I had understood</td>
</tr>
<tr>
<td><strong>019</strong> and got… and I had been told it was a ‘do not resuscitate’</td>
<td><strong>016</strong> she had not progressed well during the course of the stay here</td>
</tr>
<tr>
<td><strong>020</strong> but actually it was a ‘limited code’.</td>
<td><strong>017</strong> and had continued to deteriorate till the point</td>
</tr>
<tr>
<td><strong>021</strong> Report didn’t sound too horrible</td>
<td><strong>018</strong> where they finally had talked to the family the night before</td>
</tr>
<tr>
<td><strong>022</strong> or scare me too much.</td>
<td><strong>019</strong> and got… and I had been told it was a ‘do not resuscitate’</td>
</tr>
<tr>
<td>Line</td>
<td>Text</td>
</tr>
<tr>
<td>------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>023</td>
<td>They just said she wasn’t doing well and the family…</td>
</tr>
<tr>
<td>024</td>
<td>Nobody talked about that there’s imminent death</td>
</tr>
<tr>
<td>025</td>
<td>or ‘probably not going to make it’</td>
</tr>
<tr>
<td>026</td>
<td>that’s where you get a little more concerned.</td>
</tr>
<tr>
<td>027</td>
<td>You know if somebody says,</td>
</tr>
<tr>
<td>028</td>
<td>I think she’s going to be dead by noon,</td>
</tr>
<tr>
<td>029</td>
<td>or ‘probably not going to make it’</td>
</tr>
<tr>
<td>030</td>
<td>it would have made more of an impression.</td>
</tr>
<tr>
<td>031</td>
<td>It didn’t really make an impression</td>
</tr>
<tr>
<td>032</td>
<td>till I went in and assessed the patient.</td>
</tr>
<tr>
<td>033</td>
<td>I kinda considered that she was dying when I first assessed her.</td>
</tr>
<tr>
<td>034</td>
<td>You could see that she was not doing well.</td>
</tr>
<tr>
<td>035</td>
<td>Respirations were labored and rapid,</td>
</tr>
<tr>
<td>036</td>
<td>which to me is one big signs that something is going on.</td>
</tr>
<tr>
<td>037</td>
<td>She was not real responsive.</td>
</tr>
<tr>
<td>038</td>
<td>I think they said that her pressures were like in the 90s,</td>
</tr>
<tr>
<td>039</td>
<td>but when I came in it was 60,</td>
</tr>
<tr>
<td>040</td>
<td>but she was able to respond with that still.</td>
</tr>
<tr>
<td>041</td>
<td>And then so then I looked at the code paperwork</td>
</tr>
<tr>
<td>042</td>
<td>and saw that she did need,</td>
</tr>
<tr>
<td>043</td>
<td>that we were supposed to be using vasoactives</td>
</tr>
<tr>
<td>044</td>
<td>and that so that’s when we called the doctors.</td>
</tr>
<tr>
<td>045</td>
<td>They were pretty prompt and they came within an hour.</td>
</tr>
<tr>
<td>046</td>
<td>The cardiologist had actually been in there before I did.</td>
</tr>
<tr>
<td>Line</td>
<td>Text</td>
</tr>
<tr>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>047</td>
<td>So I came out and told him and that I had gotten a pressure of 68.</td>
</tr>
<tr>
<td>048</td>
<td>and he gave me fluids.</td>
</tr>
<tr>
<td>049</td>
<td>He told me to call renal and to call the attending.</td>
</tr>
<tr>
<td>050</td>
<td>He (the renal doctor) gave me an order right over there on the phone.</td>
</tr>
<tr>
<td>051</td>
<td>He was aware of what was going on.</td>
</tr>
<tr>
<td>052</td>
<td>He gave me… Albumin which made sense because she was 3rd spacing,</td>
</tr>
<tr>
<td>053</td>
<td>she responded one time,</td>
</tr>
<tr>
<td>054</td>
<td>but not immediately after half of the bag went in.</td>
</tr>
<tr>
<td>055</td>
<td>I got one pressure that went to the 120s but within 15 minutes it was back down to the 60s.</td>
</tr>
<tr>
<td>056</td>
<td>And I got a few 90s.</td>
</tr>
<tr>
<td>057</td>
<td>When (the attending) came up, which was shortly after the pressures</td>
</tr>
<tr>
<td>058</td>
<td>and we decided to start on vasoactives,</td>
</tr>
<tr>
<td>059</td>
<td>but we told them we couldn’t run dopamine higher than 5 mics on the floor</td>
</tr>
<tr>
<td>060</td>
<td>and do you want her transferred to ICU?</td>
</tr>
<tr>
<td>061</td>
<td>And (the renal doctor) was in with him</td>
</tr>
<tr>
<td>062</td>
<td>He looked at her and said, ‘She’s dying’.</td>
</tr>
<tr>
<td>063</td>
<td>So they decide and I…..</td>
</tr>
<tr>
<td>064</td>
<td>to keep her here and run the dopamine as high as you can.</td>
</tr>
<tr>
<td>065</td>
<td>It made sense.</td>
</tr>
<tr>
<td>066</td>
<td>I gave the bolus and the albumin and pumped the dopamine.</td>
</tr>
</tbody>
</table>

And then so then I looked at the code paperwork and saw that she did need, that we were supposed to be using vasoactives and that so that’s when we called the doctors. They were pretty prompt and they came within an hour. He (the renal doctor) gave me an order right over there on the phone. He was aware of what was going on. He gave me… Albumin which made sense because she was 3rd spacing, The cardiologist had actually been in there before I did. But we told them we couldn’t run dopamine higher than 5 mics on the floor and do you want her transferred to ICU? She responded one time, but not immediately after half of the bag went in. I got one pressure that went to the 120s but within 15 minutes it was back down to the 60s. And I got a few 90s. When (the attending) came up, which was shortly after the pressures and we decided to start on vasoactives, It made sense. When (the attending) came up, which was shortly after the pressures and we decided to start on vasoactives,
<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>067</td>
<td>The attending had said to consult hospice.</td>
<td>059</td>
<td>but we told them we couldn’t run dopamine higher than 5 mics on the floor</td>
</tr>
<tr>
<td>068</td>
<td>The granddaughter was able …</td>
<td>060</td>
<td>and do you want her transferred to ICU?</td>
</tr>
<tr>
<td>069</td>
<td>to come in after that and she was able to talk with her.</td>
<td>061</td>
<td>And (the renal doctor) was in with him</td>
</tr>
<tr>
<td>070</td>
<td>She saw her grandson that she seemed to recognize.</td>
<td>062</td>
<td>He looked at her and said, ‘She’s dying’.</td>
</tr>
<tr>
<td>071</td>
<td>But she really wasn’t verbal.</td>
<td>STANZA 9 (Making sense)</td>
<td></td>
</tr>
<tr>
<td>072</td>
<td>She could nod her head…</td>
<td>063</td>
<td>So they decide and I…..</td>
</tr>
<tr>
<td>073</td>
<td>and uh.. she was in pain,</td>
<td>064</td>
<td>to keep her here and run the dopamine as high as you can.</td>
</tr>
<tr>
<td>074</td>
<td>she did say that.</td>
<td>065</td>
<td>It made sense.</td>
</tr>
<tr>
<td>075</td>
<td>I was too afraid to give any pain medication at that point</td>
<td>066</td>
<td>I gave the bolus and the albumin and pumped the dopamine.</td>
</tr>
<tr>
<td>076</td>
<td>because I had no blood pressure</td>
<td>067</td>
<td>The attending had said to consult hospice.</td>
</tr>
<tr>
<td>077</td>
<td>and I didn’t have no clear directives.</td>
<td>STANZA 10 (The family presence)</td>
<td></td>
</tr>
<tr>
<td>078</td>
<td>I wish I had medicated her for pain,</td>
<td>068</td>
<td>The granddaughter was able …</td>
</tr>
<tr>
<td>079</td>
<td>So the hospice nurse was up here,</td>
<td>069</td>
<td>to come in after that and she was able to talk with her.</td>
</tr>
<tr>
<td>080</td>
<td>did her whole evaluation</td>
<td>070</td>
<td>She saw her grandson that she seemed to recognize.</td>
</tr>
<tr>
<td>081</td>
<td>she told me that she was recommending that a palliative bed…</td>
<td>071</td>
<td>But she really wasn’t verbal.</td>
</tr>
<tr>
<td>082</td>
<td>she would recommend that they switch her to Dilaudid for her pain</td>
<td>STANZA 11 (Untreated pain and fear of medicating, remorse)</td>
<td></td>
</tr>
<tr>
<td>083</td>
<td>and get her pain controlled.</td>
<td>072</td>
<td>She could nod her head…</td>
</tr>
<tr>
<td>084</td>
<td>And that was probably the major holdup.</td>
<td>073</td>
<td>and uh.. she was in pain,</td>
</tr>
<tr>
<td>085</td>
<td>Because the granddaughter had said she was calling the daughter</td>
<td>074</td>
<td>she did say that.</td>
</tr>
<tr>
<td>086</td>
<td>when she had left at 10 in the morning.</td>
<td>075</td>
<td>I was too afraid to give any pain medication at that point</td>
</tr>
<tr>
<td>087</td>
<td>I don’t know if she (the daughter) actually had the legal power of attorney</td>
<td>076</td>
<td>because I had no blood pressure</td>
</tr>
<tr>
<td>088</td>
<td>but the one the family,</td>
<td>077</td>
<td>and I didn’t have no clear directives.</td>
</tr>
<tr>
<td>089</td>
<td>basically it was the one that the family agreed to make the decision maker.</td>
<td>078</td>
<td>I wish I had medicated her for pain,</td>
</tr>
<tr>
<td>090</td>
<td>They were just waiting for the family to talk to.</td>
<td>STANZA 12 (Plans)</td>
<td></td>
</tr>
<tr>
<td>Line</td>
<td>Text</td>
<td>Line</td>
<td>Text</td>
</tr>
<tr>
<td>------</td>
<td>----------------------------------------------------------------------</td>
<td>------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>091</td>
<td>And so we were kinda waiting for (the daughter)</td>
<td>079</td>
<td>So the hospice nurse was up here,</td>
</tr>
<tr>
<td>092</td>
<td>and hospice knew that</td>
<td>080</td>
<td>did her whole evaluation</td>
</tr>
<tr>
<td>093</td>
<td>and they had called the home</td>
<td>081</td>
<td>she told me that she was recommending that a palliative bed…</td>
</tr>
<tr>
<td>094</td>
<td>and been told that she was on her way to the hospital.</td>
<td>082</td>
<td>she would recommend that they switch her to Dilaudid for her pain</td>
</tr>
<tr>
<td>095</td>
<td>For some reason it took her 3 or more hours it seems to me,</td>
<td>083</td>
<td>and get her pain controlled.</td>
</tr>
<tr>
<td>096</td>
<td>from what I remember.</td>
<td>084</td>
<td>And that was probably the major holdup.</td>
</tr>
<tr>
<td>097</td>
<td>It was just a matter of getting (the daughter)</td>
<td>085</td>
<td>Because the granddaughter had said she was calling the daughter</td>
</tr>
<tr>
<td>098</td>
<td>and the hospice nurse together,</td>
<td>086</td>
<td>when she had left at 10 in the morning.</td>
</tr>
<tr>
<td>099</td>
<td>took 10-15 minutes to locate her (the hospice nurse) in the hospital.</td>
<td>087</td>
<td>I don’t know if she (the daughter) actually had the legal power of</td>
</tr>
<tr>
<td>100</td>
<td>Her son came up and a grandson</td>
<td>088</td>
<td>but the one the family,</td>
</tr>
<tr>
<td>101</td>
<td>and they spent some time with her…</td>
<td>089</td>
<td>basically it was the one that the family agreed to make the decision</td>
</tr>
<tr>
<td>102</td>
<td>And this whole time her pressure is stayed mostly in the 60s -70s-80s.</td>
<td>090</td>
<td>maker.</td>
</tr>
<tr>
<td>103</td>
<td>I’m trying to remember</td>
<td>091</td>
<td>They were just waiting for the family to talk to.</td>
</tr>
<tr>
<td>104</td>
<td>if we gave any other treatments in between,</td>
<td>092</td>
<td>And so we were kinda waiting for (the daughter)</td>
</tr>
<tr>
<td>105</td>
<td>just monitoring her,</td>
<td>093</td>
<td>and hospice knew that</td>
</tr>
<tr>
<td>106</td>
<td>trying to position ….</td>
<td>094</td>
<td>and they had called the home</td>
</tr>
<tr>
<td>107</td>
<td>couldn’t really give pain meds,</td>
<td>095</td>
<td>and been told that she was on her way to the hospital.</td>
</tr>
<tr>
<td>108</td>
<td>so tried to reposition her</td>
<td>096</td>
<td>For some reason it took her 3 or more hours it seems to me,</td>
</tr>
<tr>
<td>109</td>
<td>and help her that way.</td>
<td>097</td>
<td>from what I remember.</td>
</tr>
<tr>
<td>110</td>
<td>She was mostly out of it.</td>
<td>098</td>
<td>It was just a matter of getting (the daughter)</td>
</tr>
<tr>
<td>111</td>
<td>I was able to spend most …</td>
<td>099</td>
<td>and the hospice nurse together,</td>
</tr>
<tr>
<td>112</td>
<td>a lot of time in that room.</td>
<td>100</td>
<td>took 10-15 minutes to locate her (the hospice nurse) in the hospital.</td>
</tr>
<tr>
<td>113</td>
<td>Although….. When the family was in there I tried …</td>
<td></td>
<td>STANZA 15 (Family gathering)</td>
</tr>
<tr>
<td>114</td>
<td>I didn’t want to hover around.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 115 | She wasn’t changing. | 100 | Her son came up and a grandson
| 116 | She was on a bipap machine this whole time. | 101 | and they spent some time with her...
| 117 | She couldn’t really communicate because of that... | 102 | STANZA 16 (Giving Care)
| 118 | it was only when they were actually even pulling the mask away | 103 | And this whole time her pressure is stayed mostly in the 60s - 70s-80s.
| 119 | and tried to look her right in the eye | 104 | I’m trying to remember
| 120 | and talk to her; | 105 | if we gave any other treatments in between,
| 121 | they were able to get communication from her. | 106 | trying to position ….
| 122 | She had said to the daughter that she was hurting | 107 | couldn’t really give pain meds,
| 123 | and I explained to the family, | 108 | so tried to reposition her
| 124 | I said her blood pressure the way it is, | 109 | and help her that way.
| 125 | the pain medicine is likely to affect that…… | 110 | STANZA 17 (Being there)
| 126 | and it could possibly make it worse... | 111 | She was mostly out of it.
| 127 | It may make her death more imminent. | 112 | I was able to spend most …
| 128 | Do you understand that? | 113 | a lot of time in that room.
| 129 | It is a decision we can make. | 114 | Although….. When the family was in there I tried …
| 130 | The daughter lifted her mask | 115 | I didn’t want to hover around.
| 131 | and said, ‘Mom, do you want the pain medicine?’ | 116 | She wasn’t changing.
| 132 | And they talked, | 117 | STANZA 18 (Communicating with Family)
| 133 | and they said, just give her pain medicine. | 118 | She was on a bipap machine this whole time.
| 134 | And the social worker (& hospice) got together | 119 | She couldn’t really communicate because of that...
| 135 | and they were going to give the talk (to the family). | 120 | it was only when they were actually even pulling the mask away
| 136 | As they were going off to give the talk, | 121 | and tried to look her right in the eye
| 137 | I was giving the pain medicine, | 122 | and talk to her;
| 138 | by the time they got back, | 123 | they were able to get communication from her.
<p>| 139 | I had no pressure… |</p>
<table>
<thead>
<tr>
<th>Line</th>
<th>Text</th>
<th>Stanza</th>
</tr>
</thead>
<tbody>
<tr>
<td>140</td>
<td>And then were acute changes on the telemetry.</td>
<td>STANZA 19 (Getting permission from family)</td>
</tr>
<tr>
<td>141</td>
<td>She had a MI.</td>
<td></td>
</tr>
<tr>
<td>142</td>
<td>She bottomed out within 15 minutes</td>
<td></td>
</tr>
<tr>
<td>143</td>
<td>and so all of that happened all at once.</td>
<td></td>
</tr>
<tr>
<td>144</td>
<td>So the family came back,</td>
<td></td>
</tr>
<tr>
<td>145</td>
<td>they were ready,</td>
<td></td>
</tr>
<tr>
<td>146</td>
<td>they kinda knew,</td>
<td></td>
</tr>
<tr>
<td>147</td>
<td>they had had a chance to talk to hospice.</td>
<td>STANZA 20 (Family interaction)</td>
</tr>
<tr>
<td>148</td>
<td>They knew what it meant,</td>
<td></td>
</tr>
<tr>
<td>149</td>
<td>what they were doing.</td>
<td></td>
</tr>
<tr>
<td>150</td>
<td>It made the decision;</td>
<td></td>
</tr>
<tr>
<td>151</td>
<td>yes they were going to do that.</td>
<td></td>
</tr>
<tr>
<td>152</td>
<td>They didn’t really get a chance to sign,</td>
<td></td>
</tr>
<tr>
<td>153</td>
<td>but they gave their verbal</td>
<td></td>
</tr>
<tr>
<td>154</td>
<td>and hospice said, ‘get the doctor on the phone’</td>
<td>STANZA 21 (Acknowledgement)</td>
</tr>
<tr>
<td>155</td>
<td>and get the palliative bed order.’</td>
<td></td>
</tr>
<tr>
<td>156</td>
<td>They wanted the bipap removed so they could talk to her</td>
<td></td>
</tr>
<tr>
<td>157</td>
<td>and he gave me those orders on the phone right away.</td>
<td></td>
</tr>
<tr>
<td>158</td>
<td>By the time we got the bipap off,</td>
<td>STANZA 22 (The Death)</td>
</tr>
<tr>
<td>159</td>
<td>each of them.</td>
<td></td>
</tr>
<tr>
<td>160</td>
<td>I think there was three at the bedside</td>
<td></td>
</tr>
<tr>
<td>161</td>
<td>were able to kiss her.</td>
<td></td>
</tr>
<tr>
<td>162</td>
<td>And they knew we were losing her at any point.</td>
<td></td>
</tr>
<tr>
<td>163</td>
<td>Very quick… within 20 minutes.</td>
<td></td>
</tr>
<tr>
<td>164</td>
<td>I didn’t think it would be that quick…</td>
<td></td>
</tr>
<tr>
<td>165</td>
<td>But, I really thought it would be a respiratory</td>
<td></td>
</tr>
<tr>
<td>166</td>
<td>and it would be all night…</td>
<td>STANZA 23 (Acceptance)</td>
</tr>
<tr>
<td>167</td>
<td>thought there was more family coming</td>
<td></td>
</tr>
<tr>
<td>168</td>
<td>I and it would be all night.</td>
<td></td>
</tr>
<tr>
<td>169</td>
<td>You’d say I wish the family would have had</td>
<td></td>
</tr>
</tbody>
</table>
maybe more time to know

<table>
<thead>
<tr>
<th>Line</th>
<th>Text</th>
<th>Line</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>170</td>
<td>that they could have been in there.</td>
<td>147</td>
<td>they had had a chance to talk to hospice.</td>
</tr>
<tr>
<td>171</td>
<td>If maybe they would have known,</td>
<td>148</td>
<td>They knew what it meant,</td>
</tr>
<tr>
<td>172</td>
<td>maybe they would have come.</td>
<td>149</td>
<td>what they were doing.</td>
</tr>
<tr>
<td>173</td>
<td>I’m sure probably some of them get up there</td>
<td>150</td>
<td>It made the decision;</td>
</tr>
<tr>
<td>174</td>
<td>and wished they had,</td>
<td>151</td>
<td>yes they were going to do that.</td>
</tr>
<tr>
<td>175</td>
<td>that we should have called everybody in.</td>
<td></td>
<td>STANZA 24 (Patient decides)</td>
</tr>
<tr>
<td>176</td>
<td>My projection was 10-15 people up here saying goodbye,</td>
<td>152</td>
<td>They didn’t really get a chance to sign,</td>
</tr>
<tr>
<td>177</td>
<td>throughout the evening,</td>
<td>153</td>
<td>but they gave their verbal</td>
</tr>
<tr>
<td>178</td>
<td>probably be a respiratory thing,</td>
<td>154</td>
<td>and hospice said, ‘get the doctor on the phone</td>
</tr>
<tr>
<td>179</td>
<td>and that would just gradually…..</td>
<td>155</td>
<td>and get the palliative bed order.’</td>
</tr>
<tr>
<td>180</td>
<td>though the night…. occur.</td>
<td>156</td>
<td>They wanted the bipap removed so they could talk to her</td>
</tr>
<tr>
<td>181</td>
<td>I still don’t know if that medicine caused her to have an MI,</td>
<td>157</td>
<td>and he gave me those orders on the phone right away.</td>
</tr>
<tr>
<td>182</td>
<td>I think…. She had the ST elevation.</td>
<td></td>
<td>STANZA 25 (Saying goodbyes)</td>
</tr>
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<td>183</td>
<td>Could be what happened.</td>
<td>158</td>
<td>By the time we got the bipap off,</td>
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<td>184</td>
<td>Although, 0.5 of Nuban…..</td>
<td>159</td>
<td>each of them,</td>
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<td>185</td>
<td>but if it lowered the pressure …</td>
<td>160</td>
<td>I think there was three at the bedside</td>
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<td>186</td>
<td>it could be….</td>
<td>161</td>
<td>were able to kiss her.</td>
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<td>187</td>
<td>I was given the impression that the family …</td>
<td>162</td>
<td>And they knew we were losing her at any point.</td>
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<td>188</td>
<td>see even on that Friday night</td>
<td>163</td>
<td>Very quick… within 20 minutes.</td>
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<td>189</td>
<td>when they surely probably approached them with hospice,</td>
<td></td>
<td>STANZA 26 (Surprise)</td>
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<tr>
<td>190</td>
<td>they didn’t automatically go to a ‘do not resuscitate’,</td>
<td>164</td>
<td>I didn’t think it would be that quick…</td>
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<tr>
<td>191</td>
<td>the family chose limited.</td>
<td>165</td>
<td>But, I really thought it would be a respiratory</td>
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<td>192</td>
<td>So in my mind that means</td>
<td>166</td>
<td>and it would be all night…</td>
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<td>193</td>
<td>the family was probably the hold up.</td>
<td>167</td>
<td>thought there was more family coming</td>
</tr>
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<td>194</td>
<td>They were not ready to say, ‘let’s this happen’.</td>
<td>168</td>
<td>and it would be all night.</td>
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<tr>
<td>195</td>
<td>And the family didn’t change until they went</td>
<td></td>
<td>STANZA 27 (Making meaning)</td>
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<tr>
<td>196</td>
<td>and talked with the hospice nurse.</td>
<td>169</td>
<td>You’d say I wish the family would have had maybe more time</td>
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</table>
197. It was within the hour of her death.
170. that they could have been in there.
198. It just seems to me by what I saw that day,
171. If maybe they would have known,
199. that the family wasn’t ready to process.
172. maybe they would have come.
200. But I didn’t see any of that drama
173. I’m sure probably some of them get up there
201. or anything going on amongst them.
174. and wished they had,
202. Everybody seemed to be on the same page.
175. that we should have called everybody in.
203. This is end of life,
176. My projection was 10-15 people up here saying goodbye,
204. but we’re not all excited about doing something
177. throughout the evening,
heroic here.
205. Let’s just ….the course…in the kindest way
178. probably be a respiratory thing,
possible.
206. That’s the idea, so I was never really super
179. and that would just gradually…..
tense.
207. I think not traumatic because to me
180. though the night…. occur.
208. it almost worked the best way it could,
STANZA 28 (Questioning her own Actions)
209. they kinda had made the decision,
181. I still don’t know if that medicine caused her to have an MI,
210. but they didn’t really have to go through with
it…
182. I think…. She had the ST elevation.
211. One of them said,
183. Could be what happened.
212. ‘she kinda took the decision out of our hands,
184. Although, 0.5 of Nuban ….
didn’t she?’
213. And they said, yeah she did.
185. but if it lowered the pressure …
214. The daughter seemed to be relieved to hear that.
186. it could be….
215. You know I think that’s the hard part….
STANZA 29 (Family wasn’t ready)
216. I’m killing somebody…
187. I was given the impression that the family …
217. No matter how you explain it to them,
188. see even on that Friday night
218. they know it’s not…
189. when they surely probably approached them with hospice,
219. It’s still hard to …. 
190. they didn’t automatically go to a ‘do not resuscitate’,
220. So they didn’t really have to in my opinion...
191. the family chose limited.
221. I think that’s the best thing the family can get,
STANZA 30 (Hospice support)
222. is when they don’t have to make that decision. 
192. So in my mind that mean s
<p>| 223 | This is when the patient is able to make as much of the decision for themselves | 193 | the family was probably the hold up. |
| 224 | to take that guilt off. | 194 | They were not ready to say, ‘let’s this happen’. |
| 225 | And uh I think that can be comfortable there. | 195 | And the family didn’t change until they went |
| 226 | They did what she asked for. | 196 | and talked with the hospice nurse. |
| 227 | They were... The family was pretty reasonable. | 197 | It was within the hour of her death. |
| 228 | There wasn’t a lot of drama. | 198 | STANZA 31 (Assisting the family in transition) |
| 229 | Back in ‘88 my father and my sister had to sign, | 199 | that the family wasn’t ready to process. |
| 230 | for my mother who was in a coma to take the dialysis off. | 200 | But I didn’t see any of that drama |
| 231 | My sister went through two years of therapy | 201 | or anything going on amongst them. |
| 232 | and two years later and came to me | 202 | Everybody seemed to be on the same page. |
| 233 | ‘Oh, I have to apologize for killing your mother’. | 203 | This is end of life, |
| 234 | What are you talking about? | 204 | but we’re not all excited about doing something heroic here. |
| 235 | Well, and she referred to it as the day she killed her mother | 205 | Let’s just …the course…in the kindest way possible. |
| 236 | and she really had a hard time dealing with | 206 | That’s the idea, so I was never really super tense. |
| 237 | and they all knew that she was dying. | 207 | I think not traumatic because to me |
| 238 | We all knew she was dying for months, | 208 | it almost worked the best way it could, |
| 239 | I don’t think we killed her! | 209 | they kinda had made the decision, |
| 240 | Well she said, I signed that paper. | 210 | but they didn’t really have to go through with it… |
| 241 | It is a hard thing to do. | 211 | One of them said, |
| 242 | And I think that …. | 212 | ‘she kinda took the decision out of our hands, didn’t she?’ |
| 243 | That is one of the hardest things to do for your family. | 213 | And they said, yeah she did. |
| 244 | Actually I’m not upset about this one, | 214 | The daughter seemed to be relieved to hear that. |
| 245 | so no I haven’t gone home and tormented. | 215 | STANZA 33 (Patient made decision) |
| 246 | You know, I’ve thought about it | 216 | Watching people swell up with fluids seeping |
| 247 | and it brings back more horror memories from years ago….. | 217 | You know I think that’s the hard part…. |</p>
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<th>Page</th>
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<th>Text</th>
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<tbody>
<tr>
<td>249</td>
<td>and still having to …………</td>
<td>216</td>
<td>I’m killing somebody…</td>
</tr>
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<td>250</td>
<td>My goal? Is to help the family.</td>
<td>217</td>
<td>No matter how you explain it to them,</td>
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<tr>
<td>251</td>
<td>Help them find some level of comfort,</td>
<td>218</td>
<td>they know it’s not…</td>
</tr>
<tr>
<td>252</td>
<td>to make it as least traumatic as possible.</td>
<td>219</td>
<td>It’s still hard to ….</td>
</tr>
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<td>253</td>
<td>It’s a natural part of…</td>
<td>220</td>
<td>So they didn’t really have to in my opinion...</td>
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<td>254</td>
<td>I can’t believe that God didn’t intend for people to die.</td>
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<td>STANZA 34 (Prevents Guilt)</td>
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<td>255</td>
<td>Or there wouldn’t be set up the way it is that we die.</td>
<td>221</td>
<td>I think that’s the best thing the family can get,</td>
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<tr>
<td>256</td>
<td>We are supposed to die.</td>
<td>222</td>
<td>is when they don’t have to make that decision.</td>
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<td>257</td>
<td>Especially when you have somebody that is 82 or 92</td>
<td>223</td>
<td>This is when the patient is able to make as much of the decision for themselves</td>
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<td>258</td>
<td>or whatever they are supposed to die.</td>
<td>224</td>
<td>to take that guilt off.</td>
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<td>259</td>
<td>So to me the hardest lies in the family.</td>
<td>225</td>
<td>And uh I think that can be comfortable there.</td>
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<td>260</td>
<td>The family that has to live or has the trouble,</td>
<td>226</td>
<td>They did what she asked for.</td>
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<td>261</td>
<td>that has to process the death.</td>
<td>227</td>
<td>They were... The family was pretty reasonable.</td>
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<td>262</td>
<td>know I remember in CCU,</td>
<td>228</td>
<td>There wasn’t a lot of drama.</td>
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<td>263</td>
<td>I when I was a night nurse in CCU,</td>
<td></td>
<td>STANZA 35 (Own family experience)</td>
</tr>
<tr>
<td>264</td>
<td>I remember wondering, death being new…..</td>
<td>229</td>
<td>Back in ’88 my father and my sister had to sign,</td>
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<td>265</td>
<td>looking at them and all the fuss,</td>
<td>230</td>
<td>for my mother who was in a coma to take the dialysis off.</td>
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<tr>
<td>266</td>
<td>what is going on,</td>
<td>231</td>
<td>My sister went through two years of therapy</td>
</tr>
<tr>
<td>267</td>
<td>what’s right,</td>
<td>232</td>
<td>and two years later and came to me</td>
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<tr>
<td>268</td>
<td>what’s wrong?</td>
<td>233</td>
<td>‘Oh, I have to apologize for killing your mother’.</td>
</tr>
<tr>
<td>269</td>
<td>I think I did a lot more soul searching back then.</td>
<td></td>
<td>STANZA 36 (Sister’s Grief &amp; Guilt)</td>
</tr>
<tr>
<td>270</td>
<td>Out on the floor, my experience is usually is dealing more with families</td>
<td>234</td>
<td>What are you talking about?</td>
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<td>271</td>
<td>and I have become more comfortable</td>
<td>235</td>
<td>Well, and she referred to it as the day she killed her mother</td>
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<td>272</td>
<td>talking to the family about you can make decisions</td>
<td>236</td>
<td>and she really had a hard time dealing with</td>
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<td>273</td>
<td>about how much care,</td>
<td>237</td>
<td>and they all knew that she was dying.</td>
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<td>274</td>
<td>whether they need to be stuck everyday….</td>
<td>238</td>
<td>We all knew she was dying for months,</td>
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<td>275</td>
<td>and it used to be very …</td>
<td>239</td>
<td>I don’t think we killed her!</td>
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<td>276</td>
<td>that’s not my place to say anything.</td>
<td>240</td>
<td>Well she said, I signed that paper.</td>
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<td>277</td>
<td>I shouldn’t say anything.</td>
<td></td>
<td>STANZA 37 (Difficult decision)</td>
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<td>278</td>
<td>It’s not just a decision of do we pull the plug?</td>
<td>241</td>
<td>It is a hard thing to do.</td>
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<td>279</td>
<td>Or do we do everything.</td>
<td>242</td>
<td>And I think that ….</td>
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<td>280</td>
<td>It doesn’t have to be all are nothing.</td>
<td>243</td>
<td>That is one of the hardest things to do for your family.</td>
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<td>281</td>
<td>There’s many, many stages so</td>
<td></td>
<td>STANZA 38 (Felt death was OK)</td>
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<tr>
<td>282</td>
<td>and most of the time they come back thankful to know that stuff.</td>
<td>244</td>
<td>Actually I’m not upset about this one,</td>
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<td>283</td>
<td>At least they’ve always come back</td>
<td>245</td>
<td>so no I haven’t gone home and tormented.</td>
</tr>
<tr>
<td>284</td>
<td>and thanked me a lot for talking</td>
<td>246</td>
<td>You know, I’ve thought about it</td>
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<td>285</td>
<td>and taking the time to sit down and talk with them.</td>
<td>247</td>
<td>and it brings back more horror memories from years ago…..</td>
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<tr>
<td>286</td>
<td>It is much easier</td>
<td>248</td>
<td>Watching people swell up with fluids seeping out all over</td>
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<td>287</td>
<td>when you are more comfortable with</td>
<td>249</td>
<td>and still having to ...........</td>
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<td>288</td>
<td>that it is okay to say what you want to say.</td>
<td></td>
<td>STANZA 39 (Realized Goal)</td>
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<td>289</td>
<td>You are supposed to be pushing the hospital’s agenda,</td>
<td>250</td>
<td>My goal? Is to help the family.</td>
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<td>290</td>
<td>not my agenda, you know.</td>
<td>251</td>
<td>Help them find some level of comfort,</td>
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<td>291</td>
<td>The patient and family above all else.</td>
<td>252</td>
<td>to make it as least traumatic as possible.</td>
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<td>292</td>
<td>I still hopefully assume that what’s the hospital wants too…[laugh].</td>
<td>253</td>
<td>It’s a natural part of…</td>
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<td>or whatever they are supposed to die.</td>
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<td>259</td>
<td>STANZA 40 (Helping the family Process)</td>
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<td>So to me the hardest lies in the family.</td>
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<td>that has to process the death.</td>
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STANZA 41 (Experience has helped her find meaning)

I remember in CCU,

I when I was a night nurse in CCU,

I remember wondering, death being new…..

looking at them and all the fuss,

what is going on,

what’s right,

what’s wrong?

I think I did a lot more soul searching back then.

STANZA 42 (More contact with family on floor)

Out on the floor, my experience is usually is dealing more

with families

and I have become more comfortable

talking to the family about you can make decisions

about how much care,

whether they need to be stuck everyday…..

STANZA 43 (Growth as patient advocate)

and it used to be very …

that’s not my place to say anything.

I shouldn’t say anything.

It’s not just a decision of do we pull the plug?

Or do we do everything.

It doesn’t have to be all are nothing.

There’s many, many stages so

STANZA 44 (Presence)

and most of the time they come back thankful to know that

stuff.

At least they’ve always come back

and thanked me a lot for talking

and taking the time to sit down and talk with them.

STANZA 45 (Knowledge is key to comfort)

It is much easier
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<tr>
<td>287</td>
<td>when you are more comfortable with</td>
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<td>288</td>
<td>that it is okay to say what you want to say.</td>
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<td>289</td>
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<td>not my agenda, you know.</td>
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<td>The patient and family above all else.</td>
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<td>292</td>
<td>I still hopefully assume that what’s the hospital wants too…[laugh].</td>
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APPENDIX D
SAMPLE RECONSTRUCTED NARRATIVE

Nurse 3

The following is the narrative that was reconstructed from the interview with Nurse 3:

I’m trying to remember the day, it was a Monday. I don’t think I had any horrible patients, so it was easy enough to take care of and meet their needs. But it wasn’t a horrible day. I’m sure I spent more time there than any other patient. I didn’t have any major complaints or issues or problems…. I wasn’t screaming and [laugh] it was busy enough, there wasn’t no time off…. It wasn’t a bad day like I said. I had only had her the one day. So I just picked her up that morning. From what I had understood she had not progressed well during the course of the stay here and had continued to deteriorate till the point where they finally had talked to the family the night before and got… and I had been told it was a ‘do not resuscitate’ but actually it was a ‘limited code’.

Report didn’t sound too horrible or scare me too much. They just said she wasn’t doing well and the family… Nobody talked about that there’s imminent death or ‘probably not going to make it’ that’s where you get a little more concerned. You know if somebody says, I think she’s going to be dead by noon, something like that, it would have made more of an impression. It didn’t really make an impression till I went in and assessed the patient. I kinda considered that she was dying when I first assessed her. You could see that she was not doing well. Respirations were labored and rapid, which to me is one big signs that something is going on. She was not real responsive. I think they said that her pressures were like in the 90s, but when I came in it was 60, but she was able to respond with that still.

And then so then I looked at the code paperwork and saw that she did need, that we were supposed to be using vasoactives and that so that’s when we called the doctors. They were pretty prompt and they came within an hour. The cardiologist had actually been in there before I did. So I came out and told him and that I had gotten a pressure of 68 and he gave me fluids. He told me to call renal and to call the attending. He (the renal doctor) gave me an order right over there on the phone. He was aware of what was going on. He gave me… Albumin which made sense because she was 3rd spacing, she responded one time, but not immediately after half of the bag went in. I got one pressure that went to the 120s but within 15 minutes it was back down to the 60s. And I got a few 90s. When (the attending) came up, which was shortly after the pressures and we decided to start on vasoactives, but we told them we couldn’t run dopamine higher than 5 mics on the floor and do you want her transferred to ICU and (the renal doctor) was in with him? He looked at her and said, ‘She’s dying’.

So they decide and I….. to keep her here and run the dopamine as high as you can. It made sense. I gave the bolus and the albumin and pumped the dopamine. The granddaughter was able … to come in after that and she was able to talk with her.
She saw her grandson that she seemed to recognize. But she really wasn’t verbal. She could nod her head… and uh… she was in pain, she did say that. I was too afraid to give any pain medication at that point because I had no blood pressure and I didn’t have no clear directives. I wish I had medicated her for pain, the attending had said to consult hospice.

So the hospice nurse was up here, did her whole evaluation she told me that she was recommending that a palliative bed… she would recommend that they switch her to Dilaudid for her pain and get her pain controlled. And that was probably the major holdup. Because the granddaughter had said she was calling the daughter when she had left at 10 in the morning. I don’t know if she (the daughter) actually had the legal power of attorney but the one the family, basically it was the one that the family agreed to make the decision maker. They were just waiting for the family to talk to.

And so we were kinda waiting for (the daughter) and hospice knew that and they had called the home and been told that she was on her way to the hospital. For some reason it took her 3 or more hours it seems to me, from what I remember. It was just a matter of getting (the daughter) and the hospice nurse together, took 10-15 minutes to locate her (the hospice nurse) in the hospital. Her son came up and a grandson and they spent some time with her… And this whole time her pressure is stayed mostly in the 60s-70s-80s. I’m trying to remember if we gave any other treatments in between, just monitoring her, trying to position … couldn’t really give pain meds, so tried to reposition her and help her that way. She was mostly out of it. I was able to spend most … a lot of time in that room. Although… When the family was in there I tried … I didn’t want to hover around.

She wasn’t changing. She was on a bipap machine this whole time. She couldn’t really communicate because of that… it was only when they were actually even pulling the mask away and tried to look her right in the eye and talk to her; they were able to get communication from her. She had said to the daughter that she was hurting and I explained to the family, I said her blood pressure the way it is, the pain medicine is likely to affect that…… and it could possibly make it worse… It may make her death more imminent. Do you understand that? It is a decision we can make. The daughter lifted her mask and said, ‘Mom, do you want the pain medicine?’ And they talked, and they said, just give her pain medicine.

And the social worker (& hospice) got together and they were going to give the talk (to the family). As they were going off to give the talk, I was giving the pain medicine, by the time they got back, I had no pressure… And then were acute changes on the telemetry. She had a MI. She bottomed out within 15 minutes and so all of that happened all at once. So the family came back, they were ready, they kinda knew, they had had a chance to talk to hospice. They knew what it meant, what they were doing. It made the decision; yes they were going to do that. They didn’t really get a chance to sign, but they gave their verbal and hospice said, ‘get the doctor on the phone and get the palliative bed order.’ They wanted the bipap removed so they could talk to her and he gave me those orders on the phone right
away. By the time we got the bipap off, each of them, I think there was three at the bedside were able to kiss her. And they knew we were losing her at any point. Very quick… within 20 minutes.

I didn’t think it would be that quick…But, I really thought it would be a respiratory and it would be all night… I thought there was more family coming and it would be all night. You’d say I wish the family would have had maybe more time to know that they could have been in there. If maybe they would have known, maybe they would have come. I’m sure probably some of them get up there and wished they had, that we should have called everybody in. My projection was 10-15 people up here saying goodbye, throughout the evening, probably be a respiratory thing, and that would just gradually …..Though the night…. occur. I still don’t know if that medicine caused her to have an MI, I think…. She had the ST elevation. Could be what happened. Although, 0.5 of Nuban …. but if it lowered the pressure … it could be….

I was given the impression that the family …see even on that Friday night when they surely probably approached them with hospice, they didn’t automatically go to a ‘do not resuscitate’, the family chose limited. So in my mind that means the family was probably the hold up. They were not ready to say, ‘let’s this happen’. And the family didn’t change until they went and talked with the hospice nurse. It was within the hour of her death. It just seems to me by what I saw that day, that the family wasn’t ready to process. But I didn’t see any of that drama or anything going on amongst them. Everybody seemed to be on the same page. This is end of life, but we’re not all excited about doing something heroic here. Let’s just ….the course…in the kindest way possible. That’s the idea, so I was never really super tense. I think not traumatic because to me it almost worked the best way it could, they kinda had made the decision, but they didn’t really have to go through with it… One of them said, ‘she kinda took the decision out of our hands, didn’t she?’ And they said, yeah she did. The daughter seemed to be relieved to hear that. You know I think that’s the hard part…. I’m killing somebody… No matter how you explain it to them, they know it’s not… It’s still hard to …. So they didn’t really have to in my opinion… I think that’s the best thing the family can get, is when they don’t have to make that decision. This is when the patient is able to make as much of the decision for themselves to take that guilt off. And uh I think that can be comfortable there. They did what she asked for. They were... The family was pretty reasonable. There wasn’t a lot of drama.

Back in ’88 my father and my sister had to sign, for my mother who was in a coma to take the dialysis off. My sister went through two years of therapy and two years later and came to me ‘Oh, I have to apologize for killing your mother’. What are you talking about? Well, and she referred to it as the day she killed her mother and she really had a hard time dealing with and they all knew that she was dying. We all knew she was dying for months, I don’t think we killed her! Well she said, I signed that paper. It is a hard thing to do. And I think that ….That is one of the hardest things to do for your family.
Actually I’m not upset about this one, so no I haven’t gone home and tormented. You know, I’ve thought about it and it brings back more horror memories from years ago…..Watching people swell up with fluids seeping out all over and still having to ………..My goal? Is to help the family. Help them find some level of comfort, to make it as least traumatic as possible. It’s a natural part of… I can’t believe that God didn’t intend for people to die. Or there wouldn’t be set up the way it is that we die. We are supposed to die. Especially when you have somebody that is 82 or 92 or whatever they are supposed to die. So to me the hardest lies in the family. The family that has to live or has the trouble, that has to process the death.

I know I remember in CCU, when I was a night nurse in CCU, I remember wondering, death being new…..looking at them and all the fuss, what is going on, what’s right, what’s wrong? I think I did a lot more soul searching back then. Out on the floor, my experience is usually is dealing more with families and I have become more comfortable talking to the family about you can make decisions about how much care, whether they need to be stuck everyday….and it used to be very … that’s not my place to say anything. I shouldn’t say anything. It’s not just a decision of do we pull the plug? Or do we do everything. It doesn’t have to be all are nothing. There’s many, many stages so and most of the time they come back thankful to know that stuff. At least they’ve always come back and thanked me a lot for talking and taking the time to sit down and talk with them. It is much easier when you are more comfortable with that it is okay to say what you want to say. You are supposed to be pushing the hospital’s agenda, not my agenda, you know. The patient and family above all else. I still hopefully assume that what’s the hospital wants too… [laugh].
APPENDIX E
NARRATIVE ANALYSIS REPORTS

Nurse 1

Level One: Attending to Experience:

She told her story about her experience caring for a patient that was dying of liver failure. She had cared for the patient for over two years as he received two failed liver transplants. He died ten hours after she completed her shift, just before she returned to work the next evening. This death was a significant event in her career; Nurse 1 continues to pray for the patient and his family and states that this particular patient will be remembered by her for the rest of her life.

Just that I really enjoyed taking care of this patient, I really enjoyed being with the family. It will be a patient that I will remember all of my life. Not only him, but also his wife. I still pray for him every day, you know. I do consider them to be family, because I still pray for them every day.

Level Two: Telling

The interview took place in the evening at Nurse 1’s home. We were undisturbed. I have known Nurse 1 for over 10 years. I have known her for more than 13 years and she is one of my closest friends; we had worked together and have shared many personal experiences. I was present when she was critically ill and near death and her long recovery. We had discussed our views on palliative care in the past and found that we shared similar beliefs. We also would pray with our patients and supported each other in an environment that did not condone this practice. I feel she felt comfortable talking with me about this subject because when a patient was dying, we would take turns sitting with the patient if no family was present.

The interview was recorded for 52 minutes and 49 seconds. She spoke 5452 words or 90.3% of the total interview. During the interview, her voice sounded tired and sad (she had worked the night before); it was low and monotone. There was some laughter when we shared some of our past experiences together. Her voice reflected her anger when she spoke about the
patient being assigned a float nurse when he died. Frequently (127 times) during the interview she said “you know”, especially when she was agitated or spoke of things that were causing her distress.

That, *you know*, I was grateful to the fact that the family was finally saying enough was enough because we had all though that, *you know*, they probably should have given up much sooner than they actually did but the family needed the time and his kids were having a very hard time with it and I think they all needed time to deal with it. *You know* the death of their father you know the fact that they, that he was dying they had to come to it himself. And *you know* when they were ready; he finally passed within a couple of days.

*Level Three: Transcribing*

The recording was transcribed verbatim by me. The transcript then was transferred to a table format so that notes could be made on the side. The recording was then replayed and notes on the transcript was made to note voice deflections and compared to field notes. This process was repeated several times to allow reflection and thoughtfulness.

During this phase of transcribing the narrative was examined for a general plot. N1’s story is about how she utilizes her career as a nurse to be her vocation and to “do God’s work”; there is a profound sense of spirituality in her story. She utilizes her beliefs and her own personal experience with serious illness to guide her interactions with the patients and families. It is her belief system or faith in God through prayer that she finds renewal so that she can return back to work each day.

I enjoy dealing with the dying patient. like dealing with the patients that are difficult to deal with, dealing with the patient that is dying and I usually get the patients that nobody else wants to take care of.

I go to mass in the morning when I leave work. And I say, and I pray before I go in, I say a Rosary on my way to work and my faith is what keeps me going. I don’t consider nursing a job, it’s my vocation. I think that I’m here to do God’s work. It’s true, there are certain things that you do for a paycheck and there are certain things you do because you are intended, intended to do. You know. I don’t think you can be a nurse for a paycheck, there is too much emotional involvement, too much of yourself goes into it. It is my faith that rekindles me, you know. Hey sometimes I’ll
come home and I’ll you know I’ll talk to my husband and I’ll talk to my son and I’ll get upset and you know my husband will tell me his stories and stuff like that, you know he is a nurse too. And he will tell me his stories and we will kinda bounce things off of each other and help to get through things. But it is my faith that keeps me going.

*Level Four: Analyzing the Story*

The next step was to remove the interviewer’s words and to arrange the narrative into shorter phrases on separate lines. Each line was numbered, 1-1004. This was printed out and the researcher made notes on the paper version to mark when she began to tell her story and where the story ended and if there was more than one story. N1 spent a good part of the beginning of the interview discussing the medical aspects of the patient. Her story began when she described her relationship with the patient and family. The transcript lines were then rearranged to capture N1’s story and to delete any extraneous details. An outline was created to guide the reconstruction of N1’s story.

I. Introduction
II. Background – Setting the stage
III. The Experience – Caring for the dying patient
IV. The Death
V. Aftermath & Ending

Then the story was reconstructed using this outline in written paragraph format. The reconstructed narrative is 3,174 words. Data reduction and deconstruction continued until the core narrative was obtained. The format was again re-transcribed into short phrases with numbered lines. These phrases were then rearranged into “Stanzas” to provide Poetic Structure of the story; this form of analysis “is an ideal realization of the text, because it excludes interactions between teller and listener, false starts, pauses, discourse markers, nonlexical expressions, and other features of spoken language” (Riessman, 1993, p. 44). The following written report is the descendant of this analysis.
Nurse 1 framed her story that she finds her work on her unit as challenging, but fulfilling and she especially enjoys caring for the dying. This theme is present throughout the narrative from beginning to end. She talks about how she is happy to take the patients that no one else wants to care for because they are demanding and needy.

It can be very emotionally challenging working on our floor because… literally all of our patients are under a death sentence. It is very difficult; I enjoy dealing with the dying patient.

I usually get the patients that nobody else wants to take care of… usually the ones that are the most demanding, the most needy……. Taking the patients that are the most difficult. [Laugh] The most difficult to take care of but that is what I enjoy. I enjoy dealing with the dying patient. I usually get the patients that nobody else wants to take care of…. The most difficult to take care of but that is what I enjoy.

Her spirituality helps her deal with her demanding and needy patients. This profound spirituality is present throughout her entire narrative. Prayer is an important part of her nursing. She has religious rituals of prayer that assist her. She uses prayer before she goes to work.

I say my prayers before I go into work. One of the prayers that I say is please, Lord let me take care of the person that needs me the most, this night, let me be with the patient that needs me the most.

Nurse 1 feels grateful to God for the opportunity to care for the patients. She prays for her patients and herself.

Then in the morning when I’m leaving, I say a prayer for my patient. I thank God for letting me be there and I just hope that I did the best that I could for my patient, but I always pray before I go in and I pray when I leave.

The story that Nurse 1 told was about her relationship with this patient and family. She developed a special bond with them over a two year period. They shared prayer together and sense of community in their spirituality. Although she didn’t say the word love, she did feel that they were like family because they had shared conversations about each other’s family members.
I had become very close to both this man (the patient) and his wife. I had met him before was actually transplanted. The wife used to come, even if I didn’t have him as a patient, used to come find me. I’d be taking care of other patients; she’d want me to go pray with him or would tell me what was going on with her husband or whatever he had. I would go in and we would talk about the different things he’d talk about his daughter and his son and all that kind of stuff I’d tell him about my son and we’d be talking all the time. They became like family.

This long term close relationship with the patient made his death difficult for Nurse 1. She had watched him decline for months or “dying in inches”. She reflected that she had watched him progress through the stages of dying. It seemed to be the hardest for her when his neurological status changed because they weren’t able to converse as before. She still would talk to him and share her life with him, even if he couldn’t participate. These quotes depict the grief and sorrow from that Nurse 1 was also experiencing during the patient’s decline.

He was very, very intelligent man and very outgoing, very smart. I know that he was such a go-getter and he had so much life to him. To get to see him when he wasn’t really all that sick… when he became just a shell.

So it was very, very difficult because we watched him go through all kinds of changes, completely deteriorating... how he was dying inches. He went through all of the stages. He went through the denial, the anger. He went through all those stages; you could see it all. And being part of that it was difficult to watch. When he started going through all of those neuro changes and everything like that it was hard. It was really hard though he couldn’t really respond to me a lot of times I’d just go in and tell him my stories.”

Nurse 1 spoke of the faith that the family had that the patient would recover and denial that the treatments offered by the medical team were helping. She illustrates in the following quotes how the family progressed to acceptance because they realized he was suffering.

The family didn’t want to give up on him, initially. They were doing all kinds of treatments to keep him alive. She (the wife) was very, very religious; she really thought that God was going to perform a miracle and that he was going to be cured. But she was going to accept whatever needed to be.

But it was the kids that were having such a hard time and it turned out to be the kids were the ones the support for her (the wife). She was the one who actually broke down. Finally they decided that this would be enough. He had suffered enough. Actually it was good that the kids got to see how really bad he was and I
think they were probably grateful by the time he died. When they were ready; he finally passed within a couple of days.

There was some reluctance in the medical staff to accept that the patient was dying as evidenced by the talk of attempting another transplant. Nurse 1 and her colleagues were grateful that the team changed their approach from aggressive treatments to palliative care. She found solitude by feeling that his death “was a blessing” so he didn’t have to suffer any more.

We were just so grateful that they didn’t give him another one (transplant). It would have been horrible. There was no way he could have survived it. Nothing was going to help him so they decided to put him on hospice. But I really think it was a blessing that he did die.

She also felt once palliative care was initiated, the patient “was finally resigned to the fact that he was going to die” and “he had peace”.

It was important to Nurse 1 that the patient and family did not be abandoned by the team now that palliative care had been initiated. She felt that the patient and family would get better care from the staff that had journeyed with them and knew them so well than from a new team either in an inpatient hospice or in their home which was not local.

They were going to transfer him out and they decided no, but they were just going to let him stay where he was. And that he really needed to die with us at the hospital because we were the ones who were giving her the support. We were the ones who were giving him the care that he needed. She was grateful for the fact that they were allowing him to die there. Taking him out of the hospital and having him die at home would not be as beneficial to him or to them.

Nurse 1 summarizes her feelings and relationship she had with the patient and the impact it had on her. She elaborated why caring for this patient was so significant to her.

Because I had seen how he was before and he his neuro had just decompensated to such a horrible degree, that to me, it was a blessing. I was grateful to the fact that the family was finally saying enough was enough because we had all though that they probably should have given up much sooner than they actually did. I think they all needed time to deal with it.

Sometime I think you are closer to certain patients than you are to others. I think the emotional connection was stronger because I had known them for so long; he
had been in and out so many times. And I think too, because I knew that he was a religious man, a religious person. I felt comfortable crying with them, because I knew that they were religious, where lots of times you don’t know where people are in their journey. You just got to be careful nowadays. We used to go in and pray with everybody and it wasn’t so much a big deal... Now you feel like people report you if they think you are too religious. So you just wonder where people are in their spiritual journey

Nurse 1’s spirituality is evident in that she felt blessed she was able to focus on the care of this patient. She describes how she altered her normal routine by not spending as much time with her other patients and doing extra things for them.

It was a blessing too because it was slow that night I got to spend a lot of time. I didn’t need to be running. So I got to spend a lot of time with them. Well, I tried to get the other patients taken care of as quickly as possible I didn’t spend as much time....normally I spend a lot of time talking with my patients. I do a lot of extra things like backrubs, and all that kind of stuff. But instead what I did was get as much done as I could so I could be available. I tried to get my charting up to date, as much as I could in case he did go down more or he did die, so I could be available because he was so close to dying I was hoping that I would be there with him when he passed.

It was basically comfort care. We were turning him and positioning him. A lot of family interaction. A lot of verbalizing but the actual care was the same of any dying patient.

Nurse 1 was very protective of her patient and the family. She tried to be supportive and be reassuring that he would receive excellent care. She prayed with the family and had them, not other staff to assist her in the physical tasks to care for the patient.

Before the wife left she wanted to make sure that everyone knew and how everything needed to be very perfect. So I spent a lot of time with her to make sure that she knew that I knew exactly what she wanted and that I would carry on what she wanted.

The tech that I had …wasn’t… she was one of those rough people she was….couldn’t be bothered, needed to get on to the next person and that kind of stuff And that was kind of the reason I kinda chased her out of the room I felt that if she was upsetting me, she would really be upsetting the family. [Laugh] She was upsetting me, because I knew she didn’t want to be there.

And I let the daughter stay in the room when we went in to turn and position. The daughter and I ended up taking care of him. She talked about her father the kind of
father he was. I prayed with the daughter and the patient. I had prayed with the wife before she went home.”

Unlike the tech or nursing assistant, Nurse 1 believes that caring for a dying patient is important, not only for the patient but for the family. She wanted to be with the patient and family at the time of death. Her religion and spirituality shapes her belief that death is a significant part of life.

To me it is an honor to be with someone when they pass. Because it is the most important part of life is at the death. I am a very religious person and not only to be there for the person who is dying, but also to be there for the family. I felt very close to this family, I was taking care of him the night before (his death) and I had gone home to sleep I was coming back the next night I was really hoping that I would be there but it didn’t work out that way.

Nurse 1 left at the end of her shift the next morning and the patient was still alive. She spent the day at home thinking and praying for the patient and family. She was anticipating that she would care for him when she returned to work at night.

All day long I had been thinking about going in because I knew that he was going to die that day. I felt myself praying for them. I was looking forward to going in. I knew that I was going to have him that night. I had told them the night before; if he was still alive I wanted him as my patient. So I knew that I was going to have him.

Well I walked in on the floor and I saw that the room was empty. So he had died about an hour and half before I had come in. And the family had just left right before I had come in, so I didn’t get to see them.

She described her conflicting emotions that the patient had died before she returned. She was relieved and guilty at the same time.

I felt…In a way, I was kinda relieved. But in a way I felt I felt guilty, because I felt like I should have been there And I know that it is all up to God, I’m sure that was the best thing that could have happened for the family at that time, things needed to be the way they needed to be. But I felt guilty that I wasn’t there. Does that make any sense? But at the same token I was relieved, especially when I found out from the nurse who had had him what a mess it was because, the family was hysterical, crying and they were carrying on and they didn’t want to leave.
Nurse 1 was distressed to find out that the nurse assigned to the patient was a float nurse and she did not know the patient and family. She felt that the patient and family were let down; they had chosen to remain at the hospital to die in familiar surroundings instead of leaving and going to hospice or home. She was angry.

They had been given a float nurse and of course she didn’t know the family! She couldn’t take care of her other patients and all that kind of stuff because she had to be with them I didn’t think that was right at all because they knew that he was dying. They really should have assigned a staff member to take care of his family, knowing that he was going to die ….

But I just felt so bad that they gave him that float nurse to have that day… it was such a needy family. I just think; it was wrong that they did that. It was wrong."

Nurse 1 processed her feelings about the patient’s death the rest of the night. She was concerned for the family and other transplant patients who were present. She talked with other nurses and staff about her feelings and regrets that she wasn’t present at time of death. The staff supported her by pointing out that it was out of her control.

I wanted to know all of the details. To know what had happened. I wanted to know how the family reacted. I found out that there were other transplant patients there with them I was wondering how they really reacted knowing that they could be in the same boat too… because everything is so tenuous too.

Then all night long we kept talking about it, the other staff members. We kept on talking about it I kept thinking I should have been there. I really felt that I should have been there. And they kept on saying, “It’s not up to you”. [Laugh] “You have no control over the situation.” [Laugh] You have no control, when it is his time to go; it is his time to go.

Remembering the things she did have control of brought Nurse 1 comfort. She felt that he knew that she cared about him and was present his last night alive.

I did have comfort in the fact that I did take such good care of him the night before. I did pray with him, he was alert when I left. He knew that it was me. I mean that he wasn’t talking but he knew. He said my name and he recognized me and he knew that it was me who taking care of him that kinda makes you feel good inside. It was an acknowledgement.
The death of this patient had a significant impact on Nurse 1 as evidenced by her thoughts and prayers. She had tears and joy while caring for him and his family during his journey. They had shared three momentous events in his life, two transplants or rebirths and his death. Sharing these events has left a lasting effect on her. Her faith and spirituality renews her so that she can return to work and care for her patients each day. Nursing is not a job to Nurse 1, it is her vocation.

I think I did pretty much what I needed to do for him and the family. I really enjoyed taking care of this patient, I really enjoyed being with the family. I just said I wish that I had been there for them in the end. It will be a patient that I will remember all of my life. Not only him, but also his wife. I still pray for him every day, I do consider them to be family because I still pray for them every day. My faith is what keeps me going. I don’t consider nursing a job, it’s my vocation. I think that I’m here to do God’s work. It is my faith that rekindles me. But it is my faith that keeps me going.

Prolog:

I met with N1 and asked her to read my analysis of her story and to offer any comments. I showed her my work and explained the process of analysis utilized. I showed her the poetic structure document. She read this document and the “words” document. She stated that she feels that I captured her story accurately and reading it brought back the feelings and emotions that she experienced during the period. She is still angry about the “float nurse” being assigned to the patient when he died. She described her feelings that she felt that the hospital had abandoned the patient and family because they had chosen to stay at the hospital for his death so he could be cared for by the staff that had been with him during the previous months instead of going home to die with hospice.

The patient in this story was “special” and she again stated that she felt like he was “family.” She did say that she feels better about caring for her patients and because she works less frequently now and also missed some work due to her own health issues isn’t becoming as
involved with the patients. She still feels her job is her vocation, but she is trying to only think about it when she is there and is living a much fulfilled life when not at work by her volunteering with her church and anti-abortion organizations. She also stated that the time of this patient’s death was very close to the time she had cared for her mother, mother-in-law and father-in-law while they died in her home with hospice care. She stated that her own near death experience has faded to only a memory and feels that at the time of the recording she was still very “close” to that experience too and that influenced her feelings regarding this patient’s death. But the thing that has not waivered is her spirituality and her faith in God to place her where she can benefit her patients best.

**Nurse 3**

The following is the narrative analysis report or narrative of the interview with Nurse 3:

*Level One: Attending to Experience*

This death was the first death of a patient she was caring for since leaving ICU several years earlier. It was a meaningful experience for her because the events surrounding the death in the medical-surgical unit were a good experience for her as compared to other deaths of patients when she worked in ICU.

Actually I’m not upset about this one, so no I haven’t gone home and tormented. You know, I’ve thought about it and it brings back more horror memories from years ago…..Watching people swell up with fluids seeping out all over and still having to...

*Level Two: Telling*

The interview took place in the evening after Nurse 2 completed a 12 hour day shift in a conference room in the hospital. It was very quiet, no one else was around and we were undisturbed, although we could hear an occasional overhead page. I did not know Nurse 2 or the nursing assistant in this story. I am acquainted with the physicians but have not worked with
them. She was agreeable to talk with me and opened up once she relaxed, about 10 minutes into
the interview. The interview was recorded for 47 minutes and 30 seconds. She spoke 5238 words
or 83.4% of the audio recording.

Level Three: Transcribing

The recording was transcribed verbatim by me. The transcript then was transferred to a
table format so that notes could be made on the side. The recording was then replayed and notes
on the transcript was made to note voice deflections and compared to field notes. This process
was repeated several times to allow reflection and thoughtfulness.

During this phase of transcribing the narrative was examined for a general plot. The
story’s plot was helping to transition the family to acceptance of the death as the patient was
rapidly deteriorating.

Level Four: Analyzing the Story

The next step was to remove the interviewer’s words and to arrange the narrative into
shorter phrases on separate lines. Each line was numbered, 1-646. This was printed out and the
researcher made notes on the paper version to mark when she began to tell her story and where
the story ended and if there was more than one story. Data reduction and deconstruction
continued until the core narrative was obtained. The lines were rearranged and reconstructed into
a narrative format, reduced to 2,213 words. Then the story was again re-transcribed into 292
lines. The story was then analyzed using Poetic Structure to separate into Stanza’s. Each stanza
was interpreted by the researcher for topical clarity.

Level Five: Reading

Nurse 3 begins her story by visualizing the experience. At first she had some trouble
remembering the patient; it had been almost two weeks from the event and she had only cared
for the patient on her day of death. She did not consider the day to be “horrible” even though the patient had died during her shift.

I’m trying to remember the day, it was a Monday. I don’t think I had any horrible patients, so it was easy enough to take care of and meet their needs. But it wasn’t a horrible day. I’m sure I spent more time there than any other patient. I didn’t have any major complaints or issues or problems…. I wasn’t screaming and [laugh] it was busy enough.

As she remembered the day and the patient she spoke about how the report she had received regarding the patient’s condition did not match what she saw in her assessment. The information regarding the “code status” was also incorrect.

From what I had understood she had not progressed well during the course of the stay here and had continued to deteriorate till the point where they finally had talked to the family the night before and got... and I had been told it was a ‘do not resuscitate’ but actually it was a ‘limited code’.

You know if somebody says, I think she’s going to be dead by noon, something like that, it would have made more of an impression. It didn’t really make an impression till I went in and assessed the patient. I kinda considered that she was dying when I first assessed her. You could see that she was not doing well …… She was not real responsive. I think they said that her pressures were like in the 90s, but when I came in it was 60, but she was able to respond with that still. .

Nurse 3 was alarmed that the patient’s condition appeared to be deteriorating so she checked the chart and notified the physicians of her findings.

And then so then I looked at the code paperwork and saw that she did need, that we were supposed to be using vasoactives and that so that’s when we called the doctors.

The physicians were prompt in their response and gave her orders for fluids and medications to attempt to raise her blood pressure which “made sense” to Nurse 3 as she carried out their orders. When she questioned whether the patient should be in ICU, one of the doctors said, “She’s dying.” Nurse 3 felt that she could handle the patient on the med-surg unit as hospice was consulted.
So they decide and I….. to keep her here and run the dopamine as high as you can. It made sense. I gave the bolus and the albumin and pumped the dopamine.

During this time Nurse 3 was concerned about medicating the patient for pain, she was afraid that it would further compromise her blood pressure. The daughter or decision maker did not immediately come in, despite calls from the granddaughter and hospice. Nurse 3 felt this delay and lack of clear directives hampered her care of the patient, she “wished” that she had been able to medicate the patient. Other family members visited and Nurse 3 talked about the care she gave to the patient and family.

And this whole time her pressure is stayed mostly in the 60s -70s-80s. I’m trying to remember if we gave any other treatments in between, just monitoring her, trying to position ….couldn’t really give pain meds, so tried to reposition her and help her that way. She was mostly out of it. I was able to spend most …a lot of time in that room. Although….. When the family was in there I tried … I didn’t want to hover around.

When the daughter finally came to the hospital and spoke with the patient, she gave consent for the pain medication after seeing her mother, even after Nurse 3 told her that it might lower her blood pressure more, so much it could “make her death more Imminent”. Hospice and the hospital social worker took the family away to discuss palliative care as she administered the pain medication.

As they were going off to give the talk, I was giving the pain medicine, by the time they got back, I had no pressure… And then were acute changes on the telemetry. She had a MI. She bottomed out within 15 minutes and so all of that happened all at once.

The family had agreed to palliative care after meeting with the hospice nurse and Nurse 3 notified the doctor of the changes and their consent. The family sat at her bedside as she died.

They didn’t really get a chance to sign, but they gave their verbal and hospice said, ‘get the doctor on the phone and get the palliative bed order.’ They wanted the bipap removed so they could talk to her and he gave me those orders on the phone right away. By the time we got the bipap off, each of them, I think there was three at the bedside were able to kiss her. And they knew we were losing her at any point. Very quick… within 20 minutes.
The patient’s rapid death surprised Nurse 3 and the family. She had thought it would take longer and the rest of the family would have an opportunity to come and say goodbyes but thought they probably had been informed but it took them the weekend to process the information.

I was given the impression that the family …see even on that Friday night when they surely probably approached them with hospice, they didn’t automatically go to a ‘do not resuscitate’, the family chose limited. So in my mind that means the family was probably the hold up. They were not ready to say, ‘let’s this happen’. And the family didn’t change until they went and talked with the hospice nurse. It was within the hour of her death. It just seems to me by what I saw that day, that the family wasn’t ready to process. But I didn’t see any of that drama or anything going on amongst them. Everybody seemed to be on the same page. This is end of life, but we’re not all excited about doing something heroic here. Let’s just ….the course…in the kindest way possible.

I didn’t think it would be that quick…But, I really thought it would be a respiratory and it would be all night… You’d say I wish the family would have had maybe more time to know that they could have been in there. My projection was 10-15 people up here saying goodbye, throughout the evening, probably be a respiratory thing, and that would just gradually .....Thorough the night…. occur.

She pondered whether giving the medication had speeded up the death.

I still don’t know if that medicine caused her to have an MI, I think…. She had the ST elevation. Could be what happened. Although, 0.5 of Nuban …. but if it lowered the pressure … it could be…

But Nurse 3 did not feel that the patient’s death was traumatic to her because it was rapid. She felt the family was relieved that they had not signed their consent to change to palliative care only.

I was never really super tense. I think not traumatic because to me it almost worked the best way it could, they kinda had made the decision, but they didn’t really have to go through with it… One of them said, ‘she kinda took the decision out of our hands, didn’t she?’ And they said, yeah she did. The daughter seemed to be relieved to hear that. ...

I think that’s the best thing the family can get, is when they don’t have to make that decision. This is when the patient is able to make as much of the decision for themselves to take that guilt off. And uh I think that can be comfortable there. They
did what she asked for. They were... The family was pretty reasonable. There wasn’t a lot of drama.

Nurse 3 talked about how hard it was for a family to make a decision to stop aggressive care. She spoke about how hard it had been for her sister when her mother was dying. The guilt and emotional distress can be prolonged.

You know I think that’s the hard part…. I’m killing somebody… No matter how you explain it to them, they know it’s not… It’s still hard to …. So they didn’t really have to in my opinion.

Back in ’88 my father and my sister had to sign, for my mother who was in a coma to take the dialysis off. My sister went through two years of therapy and two years later and came to me ‘Oh, I have to apologize for killing your mother’. What are you talking about? Well, and she referred to it as the day she killed her mother and she really had a hard time dealing with and they all knew that she was dying. We all knew she was dying for months, I don’t think we killed her! Well she said, I signed that paper. It is a hard thing to do. And I think that ….That is one of the hardest things to do for your family.

This patient’s death did not have a negative impact on Nurse 3. She felt that it happened the way it should have, it is “natural” and she “can’t believe that God didn’t intend for people to die” especially when they have lived to “82 or92”. She remembered having a harder time when she was a less experienced nurse while working in the coronary care unit.

Actually I’m not upset about this one, so no I haven’t gone home and tormented. You know, I’ve thought about it and it brings back more horror memories from years ago…..Watching people swell up with fluids seeping out all over and still having to ……

I know I remember in CCU, when I was a night nurse in CCU, I remember wondering, death being new…..looking at them and all the fuss, what is going on, what’s right, what’s wrong? I think I did a lot more soul searching back then.

Nurse 3 has found that she deals more with the family now while caring for patients in the medical-surgical units. She feels a sense of satisfaction because she is able to achieve her goal to help the family process the dying of a patient as well as meet the conforming to the hospital’s mission.
Out on the floor, my experience is usually is dealing more with families and I have become more comfortable talking to the family about you can make decisions about how much care, whether they need to be stuck everyday…. and it used to be very … that’s not my place to say anything. I shouldn’t say anything. It’s not just a decision of do we pull the plug? Or do we do everything. It doesn’t have to be all are nothing. There’s many, many stages so and most of the time they come back thankful to know that stuff. At least they’ve always come back and thanked me a lot for talking and taking the time to sit down and talk with them. It is much easier when you are more comfortable with that it is okay to say what you want to say. You are supposed to be pushing the hospital’s agenda, not my agenda, you know. The patient and family above all else. I still hopefully assume that what’s the hospital wants too…[laugh].


BIOGRAPHICAL SKETCH

Donna Jean Kelly Gwin was born in Marietta, Georgia and grew up living in Georgia, Tennessee and Hollywood, Florida. Ms. Gwin graduated from South Broward High School and immediately began her nursing studies at Jackson Memorial Hospital School of Nursing, graduating with a diploma in 1974. She continued her secondary education by obtaining an associate’s degree from Miami Dade Community College in general education and completing her bachelor’s of science degree in nursing from the University of Miami in 1978. She worked as an operating room nurse, nursing instructor and nursing supervisor in the early years of her career as a registered nurse.

Ms. Gwin began her graduate studies at the University of Texas at Arlington in nursing administration in 1980 but due to family commitments and numerous relocations did not complete her master’s in nursing until 2002 from Jacksonville University. During those years, Ms Gwin raised her two daughters and operated a successful franchise of Todays Temporary, a clerical staffing service from 1987-1996. Ms. Gwin received numerous awards and achievements from the business community of Jacksonville, Florida, including the prestigious “Woman Business Owner of the Year for Established Business” in 1994. Ms. Gwin became affiliated with a local hospice where she developed her interest and expertise in caring for patients and families at end of life. In 1996 after selling her business, Ms. Gwin returned to her true love of nursing and began to work at St. Luke’s, a Mayo Clinic Hospital. During her years at Mayo she worked in sub-acute care, abdominal organ transplant, and ambulatory infusion until 2002 when she became a nurse education specialist for medical-surgical nursing, end of life education and a founding member of the Palliative Care Consult Team. She is a published author in palliative care and transplant nursing care. Since 1999, Ms Gwin has also been an adjunct nursing professor at a local community college and Jacksonville University.
During her doctoral studies in philosophy of nursing sciences at the University of Florida, Ms. Gwin became interested in studying caregivers, both professional and nonprofessional. From her involvement in palliative care team, she noted that nurses, physicians and nursing assistants had stories to tell about their experiences and became aware of the need for end of life research of the experiences of caring for a dying patient in the medical-surgical units of the hospital. In the future, Ms. Gwin hopes to publish, conduct seminars and workshops based upon the findings of this study for healthcare professionals to increase their knowledge, understanding and development of skills to promote harmony in end of life care.