Understanding the Challenges of Hospice Nursing

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Understanding the Challenges of Hospice Nursing

Shoshannah Seed

Carroll College
This thesis for honors recognition has been approved for the Department of Nursing by:

Dr. Jennifer Elison (Director)  Date

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Abstract

The purpose of this research was to gain understanding of the challenges of hospice nursing related to dying individuals, their families and the professional environment of a hospice facility. Six hospice nurses participated in a 30-60 minute interview exploring the challenges of hospice nursing. Interviews took place at the place of employment in a private setting. Classic Grounded theory was used to code, collect, and analyze the data. Theoretical memoing was used during all process of research to record relationships between concepts and categories. Hospice nurses cope with daily work stressors by finding a balance between work and their personal life. The core category “finding a balance” had six subcategories: managing time, facing the challenge of working with families, letting go, taking care of yourself, falling back on your team, and setting boundaries. These findings suggest that hospice nurses learn to identify their stressors and maintain personal health and balance by relying on their team and setting boundaries between themselves and their clients. Nurses were able to take necessary actions to promote their own wellness.
Acknowledgements

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Dedication

This thesis is dedicated to all hospice nurses; they have impacted many families with their spiritual knowledge and compassion. I would also like to dedicate this to the families and patients who have benefited from hospice care.
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CHAPTER I

Background

Burnout is a common phenomenon in nursing due to the high stress. The American Nurses Association reported “how nurses felt as they left their job each day,” and overall nurses felt exhausted, discouraged, saddened, powerless, and frightened on a daily basis (Erickson & Grove, 2007, para. 5). Compassion Fatigue is a type of burnout which is a secondary stress reaction that results from wanting to help, or caring for someone who has experienced a traumatic event (Abendroth & Flannery, 2006). Hospice nurses are at high risk for compassion fatigue due to the traumatic event of death and the effect of death on the client’s loved ones (Abendroth & Flannery, 2006). Approximately 83% of hospice nurses admitted that they self-sacrificed for others in need (Abendroth & Flannery, 2006). In addition to caring for the dying client, hospice nurses are also involved in caring for their clients’ families. Hospice nurses often find themselves involved in dysfunctional family dynamics, and this can consequently add to the already mounting stress of caring too much (Holst, Lundgren, Olsen & Ishoy, 2009). The nurse’s role can become compromised with the pressure from the family to solve conflicts that may arise (Holst et al., 2009). Caring for patient symptom management is a primary focus for hospice nurses (Bailey et al., 2009). In addition to patient needs are the family’s needs related to grieving effectively. The nurse’s role is to care for both the patient and the family while maintaining a professional demeanor and distance in order to protect
the nurse’s well-being (Holst et al., 2009). The purpose of this honors thesis is to gain understanding of the challenges hospice nurses face on a daily basis.

**Hospice and Palliative Care Today**

In 2008, there were approximately 2,500,000 deaths in the U.S. Of these deaths, 963,000 individuals died while receiving hospice care (NHPCO, 2009). In addition to home hospice care, hospice nurses also work in inpatient facilities. Although there are many components to the collaborative healthcare team involved in hospice, the family remains the primary caregiver, making decisions for the terminally ill client (NHPCO, 2009). Nurses may develop a strong relationship with the family members of the client, depending on the length of stay, and may grieve along with the family. The average time that a hospice client receives care is 69.5 days (NHPCO, 2009). Research supports evidence for the belief that 68.8% of hospice clients received care at home and died in their home (NHPCO, 2009). Also 83.2% of clients receiving hospice care were 65 years and older (NHPCO, 2009). The average case load for a hospice nurse is 13 clients (NHPCO, 2009).

**History of Hospice Care**

Hospice was initially used in terms of care for dying patients by physician Dame Cicely Saunders, who also founded the first hospice, St. Christopher’s, in London (NHPCO, 2009). Saunders originally introduced the idea of hospice care to the U.S. when she lectured at Yale University in 1963 (NHPCO, 2009). After this lecture, interest in hospice began to grow in the US
and flourished into what we know as hospice care today. In 1969, Kubler-Ross published a book entitled *On Death and Dying*, which was compiled from 500 interviews of hospice patients (Kubler-Ross, 1969). This book became a best seller and also promoted home care as opposed to institutionalization of terminally ill patients (NHPCO, 2009). This beginning is what launched the interest and care for individuals who are dying.

**Palliative Care**

For the purpose of this study the terms “palliative care” and “hospice” will be used synonymously. As stated in the *Oxford Textbook of Palliative Nursing* “The goal of palliative nursing is to promote quality of life across the illness trajectory through the relief of suffering, including care of the dying and bereavement follow-up.” (Coyle & Ferrell, 2010, p. 3).

**Nurses Role in Hospice Care**

The nurse’s primary role in hospice is to manage clients’ symptoms related to the dying process. This may pose a challenge when the client's symptoms are difficult to control (Bailey et al., 2009). The hospice model defines the “patient” as the family (Coyle & Ferrell, 2010). Hospice nurses may find themselves looked to as mediators of family conflicts, but maintenance of a neutral and professional demeanor is essential when conflict arises (Holst et al., 2009). The nurse in hospice is in a unique position to create meaning and foster proper grief processes because of the client's close approaching death. Time is a factor that can create stress for the nurse especially when family is resistant to the dying process (Bailey et al.,
Ideally, the care is tailored to each individual client due to different cultural and familial values, as well as the client’s relationships with the family. A holistic approach is necessary and the ability of the hospice nurse to conform to each individual and create a working relationship as well as trust, while being aware that time is a factor (Bailey et al., 2009). All of this influences the nurse’s ability to help the family let their loved one go by effectively grieving, as well as helping the client let go of their physical existence.

**Nurses Relationships with Clients, Families, and Coworkers**

Attachment is an inevitable part of nursing; there are relationships between the nurse and the client, and family members, although not every relationship is profound and intense. A qualitative study aimed at understanding palliative nursing revealed that nurses considered their relationship with their clients a “journey” (Barnard, Hollingum, & Hartfiel, 2006). Nursing staff’s perception of death was related to how the family was able to accept the loved one’s death. A “good” death was when the family was able to accept and successfully “let go” of that family member, refraining from the denial and unrealistic expectations of the terminally ill client (Lowey, 2008). Also, the nurse’s ability to be mindful and focus on the present contributed to a successful letting go process for the families (Lowey, 2008). In addition to the stress of creating a “good” death for the loved one and the family, there are pressures related to staff relationships and expectations of the collaborative team.
The experience of a high-stress environment, such as in hospice care, can lead to burnout in nurses. A challenging work environment is directly associated with job satisfaction, because the more demanding the work the higher reward for the work done (Glasberg, Eriksson, & Norberg, 2007). However, increased workload and the inability to provide adequate care for patients contributes to a stressful work environment (Glasberg et al., 2007). Unrealistic expectations related to the actual resources to provide care are also associated with burnout (Glasberg et al., 2007). Nyatanga (2009) referred to a “culture of niceness” (p. 55) seen in hospice staff which may prevent nurses from giving honest feedback. The lack of constructive feedback and peer review causes ongoing problems with staff relationships (Nyatanga, 2009). Researchers reported maintaining a positive exterior contributed to burnout because a perceived need to stay positive would override the actual needs of the patients; therefore the nurses would ignore negative topics (such as the patient’s hospice status) in order to remain positive (Nyatanga, 2009). Conversely, in a cross-sectional study, researchers investigated burnout of Swedish health care personnel, where deadening of the conscience to avoid emotion entirely was directly related to burnout (Glasberg, 2007). Additionally, hospice nurses practice non-whistle blowing in compromising ethical situations, to maintain harmony among colleagues; consequently these individuals reported feelings of guilt and shame due to their actions (Glasberg, 2007).
Stress Physiology Theory suggests that stress causes premature aging due to the shortening of telomeres, which are caps that enclose our DNA providing continued cell replication (Nyatanga, 2009). This makes a connection between emotional stress and physical illness, where burnout can create premature aging, and physical deterioration, in addition to emotional burden (Nyatanga, 2009). Emotional stress is especially difficult for those confronted with childhood death. Morgan explained that feelings of failure contributed to high levels of stress, helplessness, anger, sadness, and guilt, developed from grief caused by not being able to save the child (Morgan, 2009). High stress is not necessarily mutually exclusive to burnout, although failing to meet patient needs creates burnout and depersonalization, therefore leading to a decrease in nursing retention (Glasber et al, 2007). Understanding the challenges faced by hospice nurses on a daily basis may help to create nurse solutions to promote a healthy work environment, improve nurse satisfaction and a more productive workplace for the nurses, consequently increasing nursing retention in hospice.
CHAPTER II

Review of Literature

This review of literature explored issues related to hospice nursing and the challenges and components of hospice care. The issues were related to the nurse-client relationship, the foundation of hospice nursing. Spirituality is an important concept that affects a nurse’s ability to care for clients that are dying. Emotional Intelligence and conflict resolution are also important aspects of the interpersonal skills necessary to thrive in the workplace. The ability of the hospice nurse to use all resources and communicate effectively with the hospice team is integral when working with dying clients and their families. In addition, the effects of stress on the nurse were emotional as well as physical and this affected the nurse’s ability to care. Compassion Fatigue is a stress reaction that is often seen in hospice nursing due to the traumatic nature of death on the family. This concept relates to the nurse’s act of self-sacrificing in order to care for the client, which negatively affects the nurse, and promotes ineffective coping strategies. These aspects of hospice care will contribute to a background for what hospice nurses face as daily challenges.

Nurse-Client Relationship

Evans and Hallett (2007) discovered that the actual presence of the nurse for the client is an important part of comfort care, as well as being there for the family. These results were reported in a hermeneutic, phenomenological study that explored 15 hospice nurses’ experiences from
one hospice north of England (Evans & Hallett, 2007). Being there for the client and family is important to the client and family; however workplace demands and the large patient workload increased stress and led to nurse burnout related to their inability to sufficiently meet client needs (Evans & Hallett, 2007). In addition, creating a space that is private and comforting, like their home would be, was important to develop lasting memories of the last living moments that were precious to both the client and the family (Evans & Hallett, 2007). The ability of nurses to create a space and be available to the patient and family for emotional support will increase their job satisfaction and ability to properly cope with the client’s eventual death.

Delivering comfort as well as spiritual care to dying clients is an important aspect in holistic palliative nursing. Bailey, Moran, and Graham, (2009) explored the experiences of 22 nurses practicing in the Republic of Ireland and found that time is a barrier for providing spiritual care for dying patients. The purpose of shorter in-patient stays was to create a plan of care and then expedite community-based palliative care (Bailey et al., 2009). In addition to time management being an issue for spiritual care, poor staffing ratios and high turnover hinder the nurse’s ability to provide spiritual care and develop a therapeutic relationship (Bailey et al., 2009). Shorter in-patient stays and giving the client a choice of when and where care will be delivered create less time to get to know the patient (Bailey et al., 2009). Less time in the hospital created less time for the hospital based nurse to create and maintain a therapeutic relationship with the client (Bailey, et al.,
2009). Although the participants noted that there was less time for client interaction, this was not evident in their documentation of care (Bailey et al., 2009).

**Advanced directives.** According to a survey of 141 nurses in the Midwest, there was increased apprehension related to discussing advanced directives with patients, and objectively discussing the course of the illness with the client (Weigel, Parker, Fanning, Reyna, & Gasbarra, 2007). This study revealed a need for more training related to end of life care (Weigel et al., 2007). Additionally, implementing this training in nursing schools, as well as hospital training for all nursing employees, would benefit nursing care and decrease apprehension toward end-of-life care (Weigel et al., 2007).

**Cultural Awareness.** A cross sectional survey carried out at the Duke University Health System surveyed 205 adults 65 years and older about their attitudes toward hospice care (Johnson et al., 2009). A “good” death for African-Americans relies on community partnerships. In addition to community involvement, home-based hospice care contributes to satisfaction in relation to hospice care for the African-American community (Johnson, Kuchibhatla, & Tulsky, 2008). This approach allows for this population to stay in their community and receive appropriate care according to their culture-based belief systems (Johnson et al., 2008). African-Americans distrust the healthcare system, especially hospice care. This distrust creates an immediate tension and stress level between the nurse and client (Johnson et al., 2009). Racial differences and attitudes towards hospice care can affect the
way care is given and received. African-Americans are less likely than Caucasians to seek palliative care (Johnson et al., 2009). African-Americans expressed a lack of trust in the healthcare system, a predilection towards life sustaining care, and religious views that contradict palliative care (Johnson et al., 2009).

**Professionalism.** Georges and Grypdonck (2002) conducted a qualitative comparative study in an academic hospital that revealed that nurses felt that maintaining a professional demeanor was more important than the relationships with patients. Avoiding being emotionally overwhelmed was a major coping theme identified by these nurses (Georges & Grypdonck, 2002). Nurses also revealed that their experiences with palliative care have caused them to become more professional and detached (Georges & Grypdonck, 2002). The nurses who chose to remain professional also took a predominantly scientific approach to nursing, by focusing on the already identified problems and related tasks (Georges & Grypdonck, 2002). Additionally, these nurses described their role as care coordinator and provider of information to physicians (Georges & Grypdonck, 2002). This research revealed nurses in an academic hospital let the workplace determine their role as a palliative care nurse. It would be beneficial to “put themselves in the position of others” (p. 792) to enhance their ability to discover the need of the patients and therefore promote well being through a caring attitude (Georges & Grypdonck, 2002).

**Dealing with Conflict**
**Personality.** Personality types have not been shown to be a factor for coping ability, and therefore personality styles should be disregarded in terms of developing more effective ways of coping (Whitworth, 2008). Conflict is seen in every aspect of life, as a result of interpersonal relationships, and is especially prominent in the nursing field due to the high stress environment. However, there was no significant statistical correlation between personality types and conflict resolution, but nurse managers need to be aware of personality factors in relation to teaching coping skills to effectively manage and resolve conflict (Whitworth, 2008).

A correlation analysis was used to determine if the personality factors of introversion or extraversion, of 97 female registered nurses living in Mississippi related to their conflict coping styles of compromising, collaborating, competing, avoiding, and accommodating (Whitworth, 2008). The findings determined that there was no relation, but further investigation would be beneficial to understanding conflict and nurse satisfaction (Whitworth, 2008).

**Emotional Intelligence.** Related to personality styles, Morrison (2008) found that emotional intelligence (EI) could foster collaboration with peer nurses and diminish the tendency to accommodate peers as an unproductive method for conflict resolution. Because nursing is such a highly emotional environment, it is especially important to develop emotional intelligence and relate that to positive conflict resolution (Morrison, 2008).
Emotional Intelligence (EI) is composed of four parts: perceiving emotions, integrating emotions into thought processes, understanding emotions, and regulating and managing emotions to stimulate emotional and intellectual growth (Morrison, 2008). EI has four major clusters, including self-awareness, self-management, relationship management, and social awareness (Morrison, 2008). These clusters were positively correlated with the ability to collaborate with peer nurses (Morrison, 2008). Being able to foster and teach emotional intelligence to increase job satisfaction for hospice nurses, as well as create a more positive way of coping through effective communication, may greatly increase job performance, and nursing retention (Morrison, 2008).

**Compassion Fatigue.** Helping the dying can be rewarding when the correct coping skills are in place, but when helping others becomes overwhelming, this can create stress and emotional exhaustion. A secondary stress reaction that stems from helping others deal with traumatic events is known as compassion fatigue (Abendroth & Flannery, 2006). A non-experimental descriptive study conducted in Florida found that 80% of 216 hospice nurses were at moderate to high risk for compassion fatigue (Abendroth & Flannery, 2006). A similar statistic of 83% of these nurses admitted that they self-sacrificed for others in need (Abendroth & Flannery, 2006). These nurses compromised their own needs for the needs of their patients, which indicated an unhealthy level of empathy (Abendroth & Flannery, 2006).
This study also confirmed that emotional support is necessary when a traumatic death has occurred, as well as support for occupational stressors (Abendroth & Flannery, 2006). The implications gained from this study are that it is important for hospice nurses to care for themselves, first and foremost, in order to maintain well-being (Abendroth & Flannery, 2006). When caring for others consumes a nurse, this becomes unhealthy and the therapeutic relationship has been compromised (Abendroth & Flannery, 2006). Hospice nurses are at moderate to high risk for CF and the major implications that stem from this are loss of nurses, and especially important is the loss of experienced nurses (Abendroth & Flannery, 2006). On average, hospice nurses have 20 years of experience and their retention affects mentoring for new nurses as well as established relationships with the collaborative team (Abendroth & Flannery, 2006)

**Physiological Effects.** Another aspect of the physiological response to stress is cortisol and cytokine levels. A cross-sectional study conducted in Japan on female hospital nurses revealed that urinary cytokine levels, a bio-indicator of stress used to predict health problems, increased in relation to conflict with physicians and the nurses’ responsibilities for patient life support care (Fukuda et al., 2008). This study concluded that urinary ANG levels (cytokines) can indicate high physical distress before nurses are conscious of their negative psychological states (Fukuda et al., 2008). Chronic stress related to high levels of ANG increases the risk of coronary heart disease (Fukuda et al., 2008). Hospice nurses under chronic stress are at risk
for developing pathologies related to constant stress and release of cytokines (Fukuda et al., 2008). Understanding the work stressors involved in life sustaining care is crucial to decreasing work stress, and therefore possible health risks for nurses.

**Coping**

**Preventing burnout.** The specific skills used to successfully cope with burnout reported by Payne, were problem solving ahead of time, self control, and actively searching out support systems (Payne, 2001). The coping skills that did not work were confrontation and escape coping (Payne, 2001). Problem-focused coping was effective, whereas emotional-focused coping was ineffective (Payne, 2001). This study implied that certain coping skills were more effective in preventing burnout than others. Specifically, planning out problem solving ahead of time was reported to be one of the most successful ways to cope (Payne, 2001). Escape coping and blocking were ineffective coping skills utilized by many hospice nurses in this study (Payne, 2007). Nurses claimed that when a patient wanted to discuss concerns about death and dying, they would redirect the topic of conversation to avoid talking about something painful (Booth, Butterworth, Hillier, & Maguire, 1996). The researchers used training and supervisor support to create an open channel for communication between the nurse and patient (Booth et al., 1996). The implications for this study were that training and supervisor support are directly related to improving the well-being of the patient (Booth et al., 1996). Nurses must be able to support their clients
and address their concerns about death and dying, therefore, they themselves need support from their hospice team.

**Spirituality.** Sixty-one nurses sampled from a bachelor’s degree nursing program in Hong Kong revealed that spirituality with God, or a Supreme Being, itself is not a key factor in contributing to spiritual care; rather, the importance of self-awareness and satisfaction with oneself allows the ability to reach out to others and care for them spiritually (Chung, Wong, & Chan, 2007).

**Inner harmony.** The ability of a nurse to be spiritually whole is directly related to his or her ability to care for a patient’s spiritual needs (Chung et al., 2007). A nurse who does not have inner harmony and satisfaction with the “self” cannot create harmony for a patient (Chung et al., 2007). For hospices nurses, this is important because bringing harmony to their clients in a time of uncertainty enhances their client’s well-being. Emphasis is needed on the academic level to prepare nursing students for spiritual care and to become aware of their spiritual integrity, as well as care for themselves, before being able to spiritually care for others. This study also found a negative relationship between religion and spirituality; they cannot be considered equal or synonymous (Chung et al., 2007).

**Making meaning.** Giving meaning to death and dying is important for palliative care nurses, because of the constant emotional stressor of bereavement which they have to endure. The stressor of seeing death on a daily basis cannot be modified; therefore, it must be dealt with in a positive
way by using effective coping, such as spiritual health and avoiding disengagement strategies (Desbiens & Fillion, 2007). Meaning-making strategies help palliative nurses cope with the death they see by giving it a meaningful purpose, enhancing their spiritual well-being (Desbiens & Fillion, 2007). This is important for nurses in the hospice field because they are put in stressful situations and must have purpose and meaning to cope. It would be helpful for these nurses to be able to identify any disengagement strategies and modify their actions to give meaning to dying which would benefit their clients and promote spiritual health (Desbiens & Fillion, 2007).

A qualitative study, including ten nurses from a hospice in England, concluded nurses who have considered their own mortality have thought about what a “good death” is and how important it is for the patient, as well as the family (Ablett & Jones, 2007). Along with awareness of mortality is awareness of spirituality, and this helps hospice nurses become more aware of patient and family needs (Ablett & Jones, 2007).

Humor. In contrast to spirituality, Ablett & Jones (2007) found that if the nurses did not put importance on existential issues, they expressed the need for a good sense of humor when working in hospice. This may indicate a defensive function in which avoidance is used to stray from important issues related to patient concerns of their imminent death (Ablett & Jones, 2007). The theme of spirituality was just one of ten others that were related to commitment and purpose these palliative care nurses described (Ablett & Jones, 2007). The implications for nursing practice are similar to those found
by Chung et al. (2007), in which being spiritually well contributes to the ability of the nurse to holistically care for the patient and the family.

**Attachment Styles.** Attachment styles can influence coping with a stressful situation. Adults who have solid attachment styles are more resilient in the face of stress and coping with death and dying (Hawkins, Howard, & Oyebode, 2007). These attachments include those developed between parents and children. Those who have not made secure attachments as children were at risk for complications in future bereavement (Hawkins et al., 2007). The major sources of stress stemmed from the actual death and dying of a patient, the high amount of work, and the nurses’ feelings of unpreparedness when it came to dealing with the emotional needs of their patients (Hawkins et al., 2007). The implications for clinical practice were to adopt effective coping styles through examining a nurse's own attachment style (Hawkins et al., 2007). This will help prepare a nurse for the process of death and dying.

One nurse stated she would feel better when she had a “good cry” and talked to her significant other about nonspecific aspects of the patient and her feelings related to the death (Barnard, Hollingum, & Hartfiel, 2006). Another explained a “good” death was dependent on the nursing team's communication skills (Bernard et al., 2006). The main themes revealed in this research were maintaining self, doing all they could to care for the patient, creating closeness with the patient, working as a team, and creating meaning for life and death (Bernard et al., 2006).
Researchers found that a nurse-client connection was inherent in the therapeutic relationship and would lead to grief and loss for the nurse related to the patient’s death (Bernard, et al., 2006). Researchers also found these nurses had a difficult time keeping work and personal lives separate, needing to find consolation within their family (Bernard et al., 2006). These findings are important to clinical nursing, because teamwork and creating meaning have been overwhelming themes in this research (Bernard et al., 2006). Research findings suggest the need for consistent staffing because teamwork is so important for palliative care (Bernard et al., 2006). In addition, regular team meetings to discuss difficult situations and debrief on moments of intense loss for the nurse would prove beneficial (Bernard et al., 2006). Another aspect of the team is the need for supportive colleagues due to the “professional bereavement” (p. 12) experienced in palliative care (Bernard et al., 2006). Utilizing counselors and specific therapies to help staff to decompress and deal with their emotions would also prove beneficial (Bernard et al., 2006).

**Summary**

It is estimated that by the year 2030, over 70 million Americans will be age 65 or older (AHA, 2007). This statistic nearly doubles from the portion of 65+ Americans today (AHA, 2007). This is important for the palliative care services, and the nurses that will be caring for this aging population. This review of literature has covered many aspects of hospice nursing, which further indicate the complex issues that are involved in nursing satisfaction,
coping, and compassion fatigue. This also indicated the need for a holistic approach to hospice nursing and in-depth training programs for inexperienced hospice nurses. This review is lacking evidence of possible nursing burnout related to high patient-to-nurse ratios that would be related to overburdening the nurse. This literature is global which cannot be generalized specifically to the United States, which may indicate need for further research in the U.S.
CHAPTER III

Methodology

The purpose of the research was to further the understanding of the daily challenges of hospice nurses. Grounded theory was suited for answering the research question in this study because it allows the underlying process of social interactions to be discovered. Grounded theory allows for the research problem and the resolution to be equally identified during data analysis. With grounded theory, the researcher must remain open minded to all situations, and not let any preconceived notions sway the data collected. Although this researcher had already begun a review of literature, this prior knowledge did not force a pre-existing hypothesis, because any prior research was not necessarily connected to the end product. Grounded theory also fits the realm of nursing because it allows for a holistic approach, and the idea that the research is never done and will open gateways of new research fits the health field in that it is ever changing and expanding on previous theories of practice.

Grounded Theory

Grounded theory is the discovery of theory from data systematically obtained from social research (Glaser & Strauss, 1967). After the research data was collected, the researcher re-worked the review of literature to ground the research categories theoretically. Therefore, the grounded theory remained intact, regardless of any prior research. Grounded theory is based on readily modifiable purpose, where the research findings guide the
researcher instead of the researcher guiding the findings (Glaser, 1978). This theory includes how humans act toward others, and react to other individuals’ actions. Human interaction and past experiences are essential in the process of death and dying because those dying want to bring meaning to their lives, nostalgically assessing their entire lives, while family supports them and appreciates their life, through mourning of their death.

**Researcher’s Bias**

Problems and solutions revealed themselves through data analysis. In qualitative methodology, the researcher is the instrument and carries out interviews and data analysis. There must be trust between the participant and the researcher so the individual does not feel threatened or judged. Developing a therapeutic relationship with the individuals was important to maintain mutual respect and trust. Personal biases of the researcher included the idea that hospice nurses may have been emotionally hardened by the constant emotional strain, from seeing death and dying on a daily basis. The researcher also assumed that spirituality may relieve the nurse’s constant emotional strain. Although it is important to recognize one’s own biases, it is imperative to refrain from letting any bias guide the focus of research or interfere with analysis.

**Participants**

The sample size for this study was six nurses who are currently working in hospice. Five participants were female and one was male. Participation was on a voluntary basis. The participants contacted the
interviewer and discuss participation. Informed consent was obtained prior to data collection. These participants were interviewed in a private mutually agreed upon setting in Helena, MT. Data collection consisted of voice recording, writing field notes, and theoretical memoing. Participants were English speaking individuals who live in Montana. All were over 21 years of age, who were experienced registered nurses. The researcher set up a time with each local hospice director and presented the research proposal to all hospice nurses and asked for volunteers. The researcher left written information about the research and contact information so any interested volunteers could contact the researcher at his or her own discretion. Interested volunteers could contact the researcher via cell phone or e-mail. Letters were approved by the necessary hospice director.

**Ethical Considerations**

The Carroll College Institutional Review Board approval was obtained prior to initiating this study. The researcher completed and passed the National Institute of Health’s certificate of “Protecting Human Research Participants.” Data was stored in a locked cabinet, with anything containing identifiable material. The voice recordings obtained from the interviews were also stored in a locked cabinet and destroyed when the research ended. No names were used and the participants were identified by numbers. Informed consent was obtained prior to the interviews, and the interviews were in a private setting (Appendix A).
Data Collection

After interviewing and obtaining information about hospice nursing from each individual’s experience, the grounded theory allowed this researcher to draw conclusions from gathered information, and then integrate any applicable related research into hypotheses. Data was collected during in-depth interviews with hospice nurses. There were open-ended and close-ended questions regarding their experiences in hospice (Appendix B). Demographic data included gender, time of work in the hospice setting, coping skills, and emotions used during that time. The participants were also asked to describe their interaction with the patients and then effects the relationships have had on their lives today. In addition, the interaction between the participants and their co-workers were described to adequately assess the entire work experience. The interviews were recorded using a voice recorder. During the interview the researcher was writing field notes including any non-verbal communication used. This researcher documented the interviews through audio recording and then transcribed the personal stories of the hospice nurses. The researcher was journaling all theoretical memoing during coding, collecting, and analyzing data.

Data Analysis

Throughout the entire research process, the researcher was collecting, coding, and analyzing data. Coding involves organizing the data into concepts. The constant comparative method was used to compare issues until the ideas began to merge (Glaser, 1978). In the beginning of data
collection, hypotheses may seem unrelated, but as categories and properties are revealed in the data, and a relation becomes evident, this will eventually form the integrated central theoretical framework, also known as the core of emerging theory (Glaser and Strauss, 1967). Review of literature is traditionally done after compiling data, but in this situation the researcher reviewed literature both before and after data compilation. This researcher wrote memos as certain ideas were formed in response to the coding method. Additionally coding took place after transcribing the interviews, to determine any overlapping themes, which provided the basis of many creative hypotheses into different research pathways. After the emerging categories were solidified, the researcher reviewed literature related to each category, to further investigate emerging themes.

Limitations

Limitations included the small number of participants and a focus on rural northwestern United States. Therefore results are not intended for generalization. The two facilities that were utilized for participants were home health agencies and therefore this research cannot be generalized to nurse’s experience related to in-patient hospice facilities.
CHAPTER IV

Results

The purpose of this research was to gain understanding of the challenges of hospice nursing related to dying individuals, their families, and the professional environment of a hospice facility. The core category of this research is “Making a Difference as a Hospice Nurse” with the following supporting categories: a) Managing time, b) Facing the challenge of working with families, c) Setting boundaries, d) Letting go, and e) Falling back on your team. A basic social process was discovered, finding a balance, with the two subcategories: taking care of self and developing inappropriate boundaries. Each category will be described and validated by the participant’s own experiences.

Core Category: Making a Difference as a Hospice Nurse

Participants believed the most important aspect of hospice nursing was making a difference in the lives of the dying patients as well as helping the families grieve effectively. One challenge identified was helping the families cope with the dying process. It was not uncommon for the patient to be at peace with the dying process but the family to be reluctant to say goodbye. The challenge lay in helping the families to understand the dying process, spiritually helping them cope with the grief associated with their loved one dying, and helping them give their loved one permission to die. Spiritually helping the dying clients was also a priority and included talking about mortality and identifying their fears and hopes about what will happen
after they have died. Keeping the patient comfortable through medication management was a main priority for the nurse. The health of the hospice nurses was a huge determinant of their ability to care. Balancing their work with having a life outside of hospice was crucial to their own mental health. Self-care involved many aspects including spirituality, social support, hobbies, having fun outside of work, and keeping work and life separate. Also knowing when to ask for help from peers was identified as a method of preventing burnout. Within the Core Category “Making a Difference” there are five challenges these nurses faced which will be described and validated below according to the participant’s own experiences: a) Managing time, b) Facing the challenge of working with families, c) Setting Boundaries, d) Letting go, and e) Falling back on your team.

**Subcategory: Managing Time**

All participants expressed the challenge of managing their time effectively. One aspect which contributed to this challenge was the variability in the day of a hospice nurse. For example, there is no set schedule and a number of issues could arise on any one home visit, which require more time than anticipated. One visit could take fifteen minutes whereas another could take two hours due to a family member not coping well or finding that a patient’s status has drastically changed. Another challenge was contacting the physician for an order and getting the medication/therapy back to the patient in a timely manner. Paper work was also a challenge related to time, due to the requirements for Medicare as well as the general protocols of
facilities related to charting. The nurses felt prioritizing, problem solving, and multitasking were main themes in being able to manage time effectively.

Participant #1 stated:

When I was a hospice case manager, the day-to-day challenges was time management, taking care of everybody that needed to be seen, dropping everything that could be dropped when somebody actively starts dying, because there’s different stages in dying, so that was your challenge to be able to juggle and see who needs to be seen and then the day to day needs of a hospice patient and their families need.

... 

The patient is the center of care, but the hospice nurse is going into the homes of the patients, and their families are also seen as part of the patient's support group and are integral to the dying process. This becomes a challenge when the families are not coping properly, and the nurse must take this into account when scheduling and trying to manage time. Participant #2 articulated:

The day to day challenges are you get a schedule, and you anticipate going to the patients' houses, and everything is going to go smoothly throughout the day, and I think the challenges come when you get to the house and or to the wherever the patient is residing, and things have changes dramatically and all of sudden you're ordering a hospice bed, you're ordering new equipment, or you need more aid, you need more medications, and so I think those are the biggest challenges, because what you think is going to go along smoothly never does usually in hospice, and you're calling doctors, and the challenges, one of the biggest challenges we find in hospice is getting hold of the doctors in a timely manner, getting the medications and then getting the medications back to the patient, so that's always a big challenge.

Hospice patients are unstable due to the progression of their disease process, and being able to anticipate their needs is important but also unpredictable. Flexibility on the nurse's part is important as well as good communication with the team, especially the doctors. Participant #3 explained:
Sometimes there’s a lapse in trying to get hold of the doctor, so you might have to wait. You might be at a visit with someone else and the doctors calling you back. I don’t necessarily like to answer my phone when I’m trying to spend time with the family or a patient, so I think that’s my biggest. That’s just the challenges that you have is the multitasking that you have to do, trying to get everything accomplished, taking care of, you know, doctors’ orders, family members . . . .

This participant discussed the importance of being able to multitask while respecting patients and their families. The patients and their families are the center of care, so meeting their emotional needs while taking care of the logistics is a challenge faced daily. Participant #5 stated:

Hospice, it’s just there’s no schedule with hospice, that’s the challenge I think you know and it’s, it’s not knowing day to day what’s going to happen, you go in and you do an intake on somebody and generally it’s making your care plan or whatever and problem solving.

For this nurse, problem solving was a way of combating the stress of not knowing what to expect when she visited her clients. Participant #6 talked about time management related to paperwork:

The challenges are paperwork (laughter). Big time, paperwork is something I do not like; it takes away from my patient time. But there’s so much of it because of the laws, Medicare laws that require a lot of documentation, and there’s a lot of redundancy in it.

This nurse was frustrated with paperwork related to the Medicare guidelines, but he also had a sense of humor towards his frustrations. All but one participant stated time management was an everyday challenge that they faced. Being able to multitask and problem solve were some ways these nurses were able to deal with scheduling, as well as setting priorities.
Subcategory: Facing the Challenge of Working with Families

As stated previously, hospice families are considered to be the patients. These interviews validated this notion. Often the nurses felt the patients were ready to die, but were reluctant to do so because the families were not ready for them to die. It is the nurse’s job to care for the clients’ symptoms, help them to accept death and die peacefully, as well as help the family to anticipate death and grief. Working with the families and meeting their needs was more of a challenge than promoting a peaceful death for the dying individual. Being drawn into the family dynamics was a challenge as well because some nurses stated they become part of the family when they go into the home, and some families look to the nurse as the peacemaker, putting them in a compromising situation. In the aspect of families not accepting that their loved one is dying, educating them on the disease process can help them to understand the inevitability of death.

Families in denial of the dying process are a challenge that is hard to face especially when they look to the nurse to save their loved one.

Participant #1 recounted:

You have to be able to be caring without being, without attaching yourself. There’s a lot of great families out there, and some of them just want to suck you right in and bring you into their family. As their nurse you’ve got to be able to allow some emotion without completely immersing yourself.

Finding a balance when working with families can be a challenge, and being conscious of one’s professional boundaries is necessary when working closely with families. Participant #1 also stated:
Burnout generally comes from, you know, high need, your families get, you know some of your families get very needy, and they start needing you for every little part from getting my father up to poop, to everything that’s going on in my own personal life and how do I need to assimilate this...

In these situations, falling back on the team for support can help relieve some of the stress of challenging families. This participant also talked about utilizing social workers when the psychosocial needs of the families were overbearing the nurse’s role. Participant #2 was in a situation where the family was looking to her for mediation:

I think the most challenging one, it’s interesting, you get a lot of family dynamics in this situation, and I went to a patients house and the plan was, he was living with his girlfriend, and he was going to move to his mom’s house, and neither party wanted that to happen. It just became a huge fight. All of a sudden grandmother and granddaughter were on the floor punching each other, and everybody’s cussing and the police had to come, and all I could keep saying was “I’m just the hospice nurse,” “I’m just the hospice nurse,” and they were looking to me to be the mediator. Look at what she did to me, look what he did to me, look at this, look at that, and I was just like, you know, I’m just the nurse. My goal is the patient, your guys’ family squabbles is beyond me. That was one of my challenging ones because here the police had to be called, and there were interviews and a visit that was going to last an hour ended up with four hours, so yeah.

This situation pulls many concepts from time management to working with families to setting boundaries. These are times of crisis and families look to the nurse for guidance, but when situations get out of hand, it’s important to know when to step back and realize the nurse is here for patient and family care, not family mediation. Participant #3 talked about being the mediator for families: “Sometimes you get challenging ones where family members aren’t always on the same page, and so you kind of have to, you know, be the
peacemaker or whatever between family members and that can be challenging too, you know.” Working with the family so that everyone understands the goals and parameters of hospice is important for communications purposes as well as beginning the grieving process. Again, the nurse needs to understand the hospice role and step back when the scope of practice is being compromised. Participant #4 affirmed:

You know, it’s an intimate situation where you have a patient in their home, and their family, it’s like one of the most intimate times of their lives. They’re just there, everything’s out there. Their dirty laundry is just who hates who, and who loves who, you know, all the stuff that’s gone on throughout the years. Everything comes out while you’re there. You try and not get too involved, but it sucks you in, unless you’re not human (laughter), if you’re human it will suck you in.

This nurse stated the inevitable; the hospice nurse will get drawn into these situations. Knowing when the nurse’s health is being compromised or when the nurse is in over his or her head is essential to being able to face these challenges productively, by using the team and other resources. Participant #5 talked about how no two families are alike, and the grieving process is different for everyone, which creates a dynamic process for the nurse:

Let’s say you have a family that’s accepting and willing for the patient, you know, through the dying process. Their grieving process is going, you know, in a structured way, and then you find the families that are just opposing that, that aren’t ready. That’s probably, with hospice that’s the biggest challenge for me, because as a nurse you learn how to problem solve. You can figure out what you need to do here or there, but you can’t plan. Nobody ever teaches you for what really happens out there you know. Nobody teaches you what to do when a daughter decides to just break down and cry and just won’t let go of you, so that’s probably the hardest part for me, is dealing with the families . . ..
This nurse suggested that knowing how to handle these situations is learned through on-the-job experience and not something that can be taught in school. Participant #6 talked about how it can be difficult to work with families that are in denial, but helping them through a challenge such as this is also very rewarding:

> You’re really helping the family more than you’re helping the patient. You know, most patients say I’m ready to go, leave me alone, let me go, keep me comfortable. That’s the easy part. The hard part is the emotional part of it, and the families that are in denial and still want to save Dad or Mom or whatever, and that’s the tough part and there’s nothing you can do about it. So helping them through that has got a lot of rewards. It’s really gratifying to see a family come to the realization that, hey, I’m ready to let go now, and the peace that comes with that, it’s really, really fun to see.

This participant stated that the client is usually ready to die, and working with him or her to control symptoms is a lot less complicated than working with families in their grief. In contrast to the challenges of working with families, seeing them come to a place where they can let their loved one die is a rewarding aspect of hospice nursing.

**Subcategory: Taking Care of Self**

According to the participants, hospice nursing is different than any other type of nursing because of the need to be spiritually sound when working with dying clients and their families, on a daily basis. All participants stated that to be a hospice nurse, one needs to know where one’s beliefs lie in regards to death and dying. Reflecting on one’s own mortality is necessary when working with these clients. Taking care of oneself as the nurse is the first step in being able to take care of dying clients. More than physical
wellness is the importance of mental health in the field of hospice nursing. The nurse is constantly taking care of everyone else, the client’s symptoms, the families grieving process, the MD’s orders, and in addition, the life stressors that are outside the workplace. Taking the time to care for oneself is key in combating burnout and maintaining stability to be able to care for clients.

One participant talked about helping clients open up about issues such as fears related to dying to help them address any concerns before they die, which if left untouched could prevent them from dying comfortably:

You just start dealing with all the issues, and continue to talk about them with your coworkers, openly. You know, how do I feel about this, how do I feel about that. You have to lay it out there. You know, number one, I think hospice is a spiritual approach, versus a medicine approach, so a lot of it is very holistic type things. You challenge your patients to think about themselves spiritually is the number one, and there’s a lot of really closed. You’re not necessarily closed minded, but kind of people who are very private about that kind of issues and don’t necessarily want to open up, but as a hospice nurse you have to make them open up because those are one of the barriers that will prevent them from dying comfortably, so you have to open up that psych part of their brain. You know, we have to talk about these things. We have to use some tools that will help you release that built up emotion, so that you can allow yourself to go. And I think that’s a challenge, um, coping with that often makes you reflect on your own mortality, and you have to put it in perspective. You know, what’s the circle of life? You know, we all are born to die, so I think in my own life it’s actually helped me kind of look at life differently, look at like for the quality of life versus the quantity kind of aspect, so I don’t think coping with it is the hard part, dealing with the families and trying to help them have that same concept. ...

This shows the inevitability of reflecting on one’s beliefs about death and the spiritual strength that is necessary to address these issues with clients and families. Participant #2 talked about how emotional and intense caring for a
client and his or her family can be and how being absent for the actual death can cause some empty feelings:

I love this work and I guess what gets me is that when I walk in the door, I know they’re gonna die, so, and they know they’re gonna die, and I guess the biggest obstacle with that or the thing I have a hard time with is sometimes I work so much with the family and a patient, and, say, I might go away for four days or on the weekend, and then they die and I miss that whole, I guess you could say climax to be able to bring it to a finale, and I don’t get to do that and then a lot of times families don’t have funerals or whatever, so there is, that’s probably a hard thing with my coping I have like an emptiness inside because all of a sudden I’ve been seeing this patient for six months, and we’ve had coffee every afternoon and all of a sudden it’s gone, and there was no closure to it.

Taking the time to grieve for a client can be helpful to maintain mental health. This is especially true when the nurse has spent many hours with the client and family. To cut off all contact suddenly without the closure of witnessing the death can be difficult for the hospice nurse. Participant #3 talked about how she cries with the families when it’s appropriate because expressing feelings is necessary to cope with all the emotions the nurse is feeling:

I cope with it by, with my spiritual faith that I have, and also by being human and, here I go (crying) see! And I also cry with them, if it’s appropriate, I cry with them, and I think it helps me because at one time I tried to stuff my feelings, and not allow that to happen and try to be the professional, but I’ve had people actually say thank you for my tears, because I know that if it’s emotional and it’s just there, I don’t try to stop it anymore because, and I think it has helped me to not stuff my feelings. I deal with it at the time. I don’t go overboard. I don’t get overly emotional in front of them, but if I see a family that is struggling because of the loss of someone they love, it’s just, I guess, the empathy I have for them, and so I, I might shed a few tears. I don’t overly like bawl or carry on, but I think it helps me to deal with all the death that we see on a day-to-day basis because sometimes I think that you could stuff your feelings, and then it comes out in other ways, and at times when you don’t want it to come out, so I think that’s how
I handle it, and my faith has a lot to do with it. I do a lot of praying, a lot of scripture study, that kind of thing, stuff to try to keep me, things, in perspective.

This participant also stated that her spirituality helps her to deal with these emotions and that she is active in her church community. She has learned with her experience in hospice that suppressing emotions can have a negative effect on other parts of one’s life, and allowing oneself to grieve with the families, when appropriate, is a healthier way to deal with grief.

Participant #4 also talked about self care:

One of the things I’m always preaching to everyone is self-care. So we try to watch each other for that, but I personally, I do things like, I get a massage every two weeks for an hour, and a half and I consciously try to leave every day and leave everything here, and I’m getting pretty good at that. For a long time when I first started hospice, I couldn’t. I worried about people once I left the office, but we have an RN on call every night, and I really learned through the years to just leave it. If something comes up, they will handle it, and they’ve been very good and I’m very confident in our team members. Anybody can do as good of a job as I can do; it took me a long time to learn that.

This nurse explained the importance of leaving work at work to keep oneself healthy. This idea also relates to being able to trust one’s coworkers and have confidence in their ability to care for clients. Taking the time out of a busy schedule for self-care is important, especially with demands outside of work.

She also enumerated:

And I think a lot of the nurses don’t realize it. I mean, a lot of them are women and they give to their families, they give to, they give, give. They’re giving to the doctors, they’re giving to their patients, they’re just kind of the middle man to give to everyone, and they really just have to self-care and be really aware of it, and a lot of them aren’t. I tell ya, and I’ll say, you know, at some point you got to start getting back, whether that’s yourself giving to yourself, like me and my massage, or you’re getting it from somewhere. You’re getting counseling or being able to talk with your coworkers, but ya do, ya
have to do a lot of self-care. You can't be a real effective nurse unless you do.

Mental health and taking time to care for oneself is a necessary foundation to becoming an effective hospice nurse. Participant #5 talked about her own experiences with death before becoming a hospice nurse and how that helped to cope with the stress of working with dying clients:

You have to know where you're at I have to know where I'm at with the dying process and death. Right now I couldn't work with a child that is dying, and I know that about me so if we had a referral for a dying child with cancer, I would ask another nurse to deal with it, and I know that about myself, and I wouldn't put myself in that situation unless need be, and then again you know maybe God would help me get through that. I don't know but I've done fairly well because when you see these people suffering and you can kind of just keep them comfortable and then let them go, it's, I don't know, how do you say this, death can be beautiful, and, um, my grandma passed away, and I don't think I would have been able to do hospice prior to my grandma dying. It was kind of my turnaround where I was kind of ok with death, um, and I never wanted her to die. We were like best friends. Her clothes were the same clothes that were in my closet. We were pretty close. Anyway, watching her suffer was horrible for me. It was traumatic, to say the least, it was traumatic, and then so finally when she did pass away, I was there when she took her last breath and just watching somebody struggle and then peace, knowing that and seeing that is my own mindset that helps me be able to deal with this . . .

This participant stated that she has to know where she is at with death and know what she can and cannot handle. It is important not to put oneself in a position that may compromise morals or beliefs, so knowing how one feels about certain aspects of death is essential to be a hospice nurse, and essential to cope with the issues pertaining to death and dying. Participant #6 talked about maintaining health outside of hospice, to decrease stress:

You have to eat right. You have to get good rest, sleep, um, I walk a lot, um, the spiritual side of me, you know, I pray, I do that. The church that we go to, we worship at, that's important. My family is very supportive, um, my church family is very supportive. You know, my friends are very supportive that
you’re a hospice nurse. They say you’re special, but I don’t think so. I think that we’re just people helping each other, so, yeah, you have to take care of yourself.

This participant voiced the importance of self-care and a support system outside of work. All participants believe that self-care is an essential component of being an effective hospice nurse whether it is in mental, spiritual, or physical health. Being able to communicate with the team and talk about issues that may be bothering the nurse is important for work support. Expressing feeling of grief for the nurses is also important because of the close relationship that they have formed with the patient and family. Overall being aware of one’s health in a holistic approach is primary to the nurse’s ability to care for dying patients and their families.

**Subcategory: Letting go**

The concept ‘Letting go’ was experienced by all participants in hospice. The dying individual has to let go of their physical being and come to the realization that they will live on in a spiritual sense. Secondly the family has to let go of the loved one and give him or her permission to die, whether that may involve forgiveness on the part of the family or not, and lastly the hospice nurse has to let go of this family unit he or she has been caring for and guiding through the journey of dying. In addition, if the patient has been in a facility, the hospice nurse has to help the traditional nurses understand that there is a different approach to hospice care and measures are no longer in place to cure an illness. Palliative care focuses on treating the symptoms and promoting comfort. This is a letting go process for the facility nurses who must step back from the traditional role and take a difference approach. Letting go can be hard for the families and helping them to open up
spiritually and deal with the underlying issues of their resistance to the dying process is a necessary component of the hospice nurse’s role, according to the participants.

Participant #1 talked about the challenges of going into facilities where the hospice nurse has to introduce the hospice process to a nurse who has only known traditional cure-based western medicine. The hospice nurse must help non-hospice oriented nurses to add a new approach for this patient, who is now dying:

But the challenges of working with facilities is, you know, is a day-to-day challenge especially when you get some of those new nurses, um, who don’t like to let go of control, and when you’re working with hospice patients, it’s a whole different approach to nursing because we’re no longer trying to save the person from dying. We’re, we’re not necessarily helping them but we’re allowing their bodies to die, so we treat the symptoms that is associated with the dying process, not necessarily trying to prevent them, but we wait till the symptoms come and then we take care of their symptoms, to make them more comfortable basically. So they’re in the nursing home or the assisted living who’s been taking care of this patient trying to keep them healthy, and doing everything they can as western medicine and taking care of them and getting them better. We’re asking them to stop that at that point, and let’s take a different approach, and sometimes they have a hard time seeing that because they’re not hospice nurses. They’re traditional nurses, so to tell them to stop that approach and let’s do this instead makes them feel like they’re not doing enough for the patient anymore because they’re so used to getting them better, using traditional medicines to get them better, and we’re no longer trying to get them better. We’re allowing them to die. That’s a hard transition for them, so being a hospice case manager, it’s your job to advocate the patient and their family with this facility, so that they can allow this process to happen.

This process may be a difficult one for the hospice nurse who is an outsider of the traditional nurse’s environment, but the main underlying issue is advocating for the patients’ rights to die with comfort and dignity. In contrast to helping traditional nurses transition from curative care to comfort care, the hospice nurse has to be
able to let go of the client and grieve properly once the client has died. Participant #2 described how she feels when she misses a death:

I love this work and I guess what gets me is that when I walk in the door, I know they’re gonna die, so, and they know they’re gonna die, and I guess the biggest obstacle with that or the thing I have a hard time with is sometimes I work so much with the family and a patient and say I might go away for four days or on the weekend and then they die and I miss that whole I guess you could say climax to be able to bring it to a finale and I don’t get to do that and then a lot of times families don’t have funerals or whatever, so there is, that’s probably a hard thing with my coping I have like an emptiness inside because all of a sudden I’ve been seeing this patient for six months and we’ve had coffee every afternoon and all of a sudden it’s gone and there was no closure to it.

Closure for the nurse is important; being able to be there for the death and see death in that moment is optimal for this nurse to feel that her job is complete. Taking the time to grieve for a client can be helpful to maintain mental health especially when the nurse has spent so much time with this client and family. To cut off all contact suddenly without the closure of being present for death can be difficult. Participant #3 expressed her emotions at the time she felt them and will cry with the families when it is appropriate:

And I also cry with them. If it’s appropriate, I cry with them, and I think it helps me because at one time I tried to stuff my feelings, and not allow that to happen and try to be the professional, but I’ve had people actually say thank you for my tears, because I know that if it’s emotional and it’s just there I don’t try to stop it anymore because, and I think it has helped me to not stuff my feelings, I deal with it at the time, I don’t go overboard, I don’t get overly emotional in front of them, but if I see family that is struggling because of the loss of someone they love, it’s just I guess the empathy I have for them, and so I, I might shed a few tears, I don’t overly like ball or carry on, but I think it helps me to deal with all the death that we see on a day to day basis because sometimes I think that you could stuff your feelings and then it comes out in other ways and at times when you don’t want it to come out...”
This nurse has experienced negative outcomes from her previous coping mechanisms of not dealing with her emotions. She has learned that she should address her feelings as they come, while maintaining a professional demeanor.

Participant #4 talked about remembering those that have died each week in the team meeting:

We do a kind of memorial service, to remember those. We light the candle and we have a poem, and we remember those that have died that week. And just talk about them and the type of people they were and the family, and that helps us deal with things too.

This participant understood that closure for the nurse is important and talking about the patients that have died that week in a confidential setting can assist in the process of letting go. Participant #5 recounted a specific situation with a family that was not ready to let go, and how they came to the point where they could effectively grieve:

Then all the while, the reason I mentioned the feeding tube, the husband kind of continues to feed her even though she, you can tell she’s not wanting it, she’s bloated, she’s showing all the signs of not digesting this feeding that they’re giving her. And just doing a lot of education, okay, she’s not going to be going through pain if you don’t do this. You’re actually causing more, and how do you explain that to somebody, you causing more pain to this person by force feeding them, really, than by just letting her be. You know, her body doesn’t need this, and he fought and he struggled and he fought. We turned the tube off finally. One night he turned it back on because he thought she looked hungry, you know, so it was like, this was a tough one for all of us because she just wasted away into nothing. Her skeleton was sticking out of her skin. It was just, ahhh, it was crazy, and it was just because nobody was ready to deal with it, and finally getting everybody ready to, you know, let go and come to terms with what was going on, and then the day that she passed I was on call and I came up and just being there for that family, it was the most amazing feeling to watch them all grieve effectively. You know, that’s a really, really good feeling.

This participant described a situation when she had to help an entire family come to terms with their loved one’s death and reach a point where they could forgive and
let go. Participant #6 described a specific family that he worked with and how giving a loved one permission to die allows him or her to die peacefully:

I had an experience once, oh, about five years ago. It was at the Waterford and the daughter was the one that didn’t want to let Dad go, and she would pamper him, and was a great caregiver, but was just not realistic about his prognosis, and about, he didn’t want to let go because of that, and he hung on, and he hung on, and he hung on, and I can remember he was getting sicker and sicker and finally she bent down over to lean over him, and she said “Dad, it’s ok if you go. I’m going to be all right.” And he passed away that afternoon. It was really kind of cool.

This example shows the importance of helping the family come to terms that their loved one is dying and the need to help them to let go and give permission to die, so that the client can have peace and not struggle to the end. Letting go is an important process for all who are involved in caring for a dying individual. Each caretaker and client must be in touch with his or her feelings and spiritual self to deal with the concept of letting someone die. Talking about these emotions and dealing with them as they are felt is necessary to effectively grieve and maintain mental health.

**Subcategory: Setting Boundaries**

Setting boundaries is an important concept for the hospice nurse. An underlying category of maintaining balance means not getting too overly involved with clients and their families. Many participants stated that this is nearly impossible, but being aware of how close one is and knowing when to step back is necessary to prevent burnout and excessive emotional grief. Keeping life and the hospice career separate was identified as important for most participants to reduce stress. But they emphasized that this practice is hard to grasp when they were first
starting out in hospice. Hospice care is a learning experience and remaining warm and caring while keeping one's distance is a skill that is learned over time.

Participant #1 stated:

I carried a large hospice load, and that's a lot of people to take care of, so when I went to work and I was consumed, and when I came and then I got to go on call, I mean, that was all starting to just wear on me. And I have my kid who's not doing well and I have multiple kids still that I'm taking care of. I have this big household. It was just starting to wear on me. I identified it and said I need to make some changes and told my bosses next office position that opens up, I would like to be moved into an office position and one opened, thank goodness, quite, pretty, within months and, um, I got to jump right into that . . . .

This nurse experienced burnout and knew that she was not able to handle everything she had in her personal life as well as the large work load she carried and was able to communicate with her superior that she preferred a position that was less stressful. She also stated:

Again being open, talking, whether it's, you know, in your personal relationships, but it's especially with your peers that you work with 'cause they all understand what you're going through. A hundred percent of them have families or obligations outside of work so they all know how important it is to talk openly about what you're going through. That's, that's the big one. Identifying it yourself that you're starting to get burnt out and not be afraid to step down or take some time off, or just remove yourself because that's important, your sanity, you can't help anyone if you're broken . . . .

First nurses need to identify that the stress levels are unmanageable and then do something about it. They must be open and honest with coworkers so they can understand the frustrations of the nurse and then help to work with the nurse by taking more clients to relieve the nurse's workload, or some other solution to help the nurse that is having trouble coping. Participant #2 talked about leaving work at work and having a separate life outside of hospice:
That’s the part, is not getting overly involved, because that is, that will stay with you for a long time. Being able to leave, if you find you’re getting too involved. You know, letting another nurse take the patient. Sometimes we have a really hard time as case managers letting go of our patients. You know, they’re ours and we want to do all of it, and we brought them to this beautiful end together, so we want to be a part of it, but I think that’s the best way is to let another nurse take the patient. And, you know, getting away, getting away from hospice, staying away from your computer, not answering your phone, that kind of stuff. You know and as you start hospice, you find that you’re so involved and then you learn it’s like, okay, I have got to leave my work when my work is done.

This nurse explained that experience is necessary for learning how to leave work at work and not be overly involved with clients and their families. Participant #3 stated:

I guess one of the most important things is to be aware of your own grief, your own mourning, also to know what’s yours and what’s theirs, to try to keep that separate so that you’re not out-stepping those boundaries, and trying to be a companion with the people instead of trying to be a know-it-all, allow them to share with you, and to be with them at that moment wherever they’re at.

This nurse emphasized boundaries with families and the need to keep the nurse’s mourning separate from what the family is feeling. Knowing when the nurse is not able to handle a case load and consciously keeping oneself aware of emotions and grief is important for balance and health. Participant #4 stated:

Well, in our work we do such a range. You know, we have a lot of people without anybody, so those are big ones for us because everybody needs someone to do emotional work with, so I think that with our staff, a lot get kind of involved with those people who don’t have family. They’re the ones we kind of grieve for when they’re gone, where others have great family, great emotional support, and they do the emotional work. You don’t get as involved, but dying brings out the best and it brings out the worst.

This participant pointed out that the clients who do not already have a support system are the ones nurses usually get overly involved with because they need more help from the nurse to do spiritual work. So, by default, the nurse becomes their
support system. Knowing from the start that a certain patient will need more support and being aware of one’s level of involvement is important to set limits for the nurse’s well-being. Participant #5 noted:

You have to know where you’re at. You have to know your boundaries, your limits, and then you can go this way, and then also leaving it, you have to leave it, you know, and your patient is ill and they’re dying and you’re not on call at five. You have to somehow figure out how to clock your brain out. You know, yes, you care about people and that’s okay, but you have to leave it so somebody, they just have to soul search or something and figure out their own way. What can I do at this time, so I can leave my work at this time, at this employment, and I think that kind of goes back to employers. They need to really realize your nurse’s health is really important, their mental health. I’m not even thinking physical health. I’m thinking their mental stability, ’cause nurses take a lot. We see a lot. We go through a lot. We do a lot, and so I think that your employers really kind of need to be aware of that too . . .

This participant talked about being able to leave one’s work when it is time to go home and mentally disengaging from client care so that when that nurse goes home, he or she will not constantly worry about how the clients is doing alone. Another aspect of a nurse’s mental health is the employer’s willingness to acknowledge the nurse’s stress and burnout levels. Participant #6 articulated:

Oh, experience has taught me to, the empathy I have for them. You keep your distance a little bit. You can still be close and warm with them and very sympathetic, and empathetic, but you know it’s hard. I’ve cried at funerals too, because I just love this person. It’s tough, but you kind of have to just learn to keep your distance a little bit. When you leave that patient, you have to shut it off and move onto the next one, you know, in your daily travels . . .

This nurse explained the importance of keeping one’s distance from clients to prevent getting too emotionally invested in the clients who are eventually going to die, while maintaining an empathetic warm demeanor. Participants agreed that leaving the work when the work is done is necessary to decrease stress levels and maintain mental stability. Also being able to keep a distance between the nurse and
client is important to prevent stress and intense grief when the client dies. It is also important to note the need for employers to check in with their nurses and make sure they are coping with their grief.

**Subcategory: Falling back on the team**

The team approach in hospice is necessary to maintain quality care and the health of the hospice nurse. Medicare requires all hospices to have a team approach, and these participants support this practice. Being able to ask team members for help is integral in dealing with burnout. Also when a nurse is having trouble helping families or clients to let go or grieve effectively, being able to bounce ideas off of team members allows for collaboration and problem solving. Team members can also intervene when they see that a nurse is struggling and take some of the nurse’s clients, or just give him or her a day off to get away, and deal with the stress that has been building. Participant #1 stated:

> Sometimes there’s a line that you have to put down and say, you know, let me get social work in there (laughter), you know, who can you talk to. I mean you just have to be able to point them in the right direction so that they can appropriately let go some of their own emotion so that they’re not, you’re not taking it on a hundred percent, and you have to rely on all your resources out there and try to take it all in as the only one that can. Otherwise you get burnt out.

This participant expressed the importance of using the team when the nurse feels overwhelmed. Taking on all the needs of the family and client is unrealistic for the case manager; the nurse must be able to use the team members to take some of the care giving pressure off of the nurse. Participant #2 voiced:

> But the burnout is definitely there with all of us to a point. We all get to that point where I just, I just can’t do it, but we bounce back real fast. We have a great team so we just work and talk amongst each other and help each other out. We do things outside of the work. So as far as just burnout, burnout, hit
the wall, no, but close, and then we all just, you know, I need this day off or I need to chart or I just cannot see that patient anymore. Everyone is really workable around that, so that works really well.

Communication with the team is essential to prevent burnout. Talking with team members and negotiating workloads if someone cannot deal with any more deaths or any situation that the nurse may need time off for is necessary to prevent burnout. Participant #3 emphasized:

I have seen frustration in my fellow hospice nurses. I don’t know if it’s necessarily burnout or not, but definitely some frustrations in areas of being very overwhelmed. I think that sometimes just having a few days off just brings them back to focus, and we have a pretty close-knit hospice team, and I think that just being able to bounce things off of each other helps that.

This participant stated the importance of taking time off when the nurse becomes overwhelmed. Talking openly and honestly about stress levels with the team is essential to maintain a healthy balance between work and a personal life. Also being able to talk with the team and gain insight when the nurse is at a roadblock with a client or family helps to ease some of the stress. Participant #5 stated:

I do think that with a hospice component, it does pull you closer together a little bit because, and we’re small, we’re a small company so we don’t have twenty nurses out there. We’ve got five, you know, so we really do rely on each other and we know each other very well. See if I kind of, and so maybe that’s a lot of the reason, just till now not realizing maybe that’s why I’m so comfortable with my job, because I know each of these nurses . . . .

This participant indicated the importance of team as well as being able to trust one’s team and know that when care is handed off to a team member that the nurse has confidence in the team member’s abilities to care for the client as well as the nurse would. Participant #6 suggested:

We have social workers here, a social worker that goes out and does counseling as well, and we have a chaplain as well, so the team, the team effort is how we help families cope, and how we cope with families.
This participant revealed that the team approach is both necessary to help families cope as well as to help the hospice nurse cope with the challenges of working with families. The team approach is necessary for hospice nurses to balance their emotions and stress through communication and support. Trusting team members is a necessary foundation for passing on care. All of these concepts of the team approach help the nurse to cope with stress and burnout that accompany caring for individuals who are dying as well as their families.

**Summary**

Balancing time, self-care, and boundaries with clients and their families is important for the health and well-being of the hospice nurse as well as for the hospice team to work cohesively. The ability of the nurse to use the team approach and trust all team members allows for fluidity in care of the client. Team members need to work together to keep their stress levels low and provide support to those who are struggling, and may need time off. Letting go of relationships with the clients and families through effective grieving is necessary for the hospice nurse to move on to the next client. If all these challenges are maintained, the hospice nurse can effectively care for dying clients and their families.
CHAPTER V

Discussion

The nurses reported that taking care of oneself, setting boundaries, letting go, and falling back on your team were ways of coping with stressful challenges they faced on a daily basis. Findings from this study indicate hospice nurses can effectively implement strategies to prevent emotional exhaustion. These nurses identified challenges such as managing time and working with families. Overall finding a balance in work and personal life was the process that influenced the nurse’s ability to cope with stressful situations. The core category throughout this research was making a difference, for patients and families. The nurses admitted they have seen fellow nurses on the edge of emotional exhaustion and the ability to combat the overwhelming stress relied on identifying fatigue and doing something proactive about it such as taking time off and relying on the team for support.

Caring for Families of the Dying Client

Facing the challenges of working with families was a concept each nurse stated was the hardest to deal with. Caring for patients in their home was difficult because it was their environment and the nurse was the outside component, as opposed to a facility for palliative care where it is not such an intimate situation. Helping families to understand that their loved one was going to die was a complicated process due to the emotional aspect, and additionally their shock and denial of the terminal stage of their love one’s illness. According to Tsaloukidis’ (2010) research, families use refusal as a
coping mechanism to deny the reality and severity of the illness. Nurses can combat this reaction by being open and honest with the families in a supportive manner. Communication should include information about the illness and education on the course the illness has taken to the point of referral to palliative care. Just being there for the families and using touch and presence was a simple way of being supportive and non intrusive in their grief (Tsaloukidis, 2010). Education was a strategy used by participants to introduce the course and severity of the illness and what was expected as it progressed. This strategy was a gentle way to introduce the dying process. Outright disclosure to family members that their loved one was going to die was not a strategy recommended by participants. Family conflict was also present at the time of a loved one’s death. Many participants stated that they found themselves in compromising situations with families who were feuding and looking to the nurse for mediation.

**Honesty.** The concept of honesty and when it was appropriate to be completely honest as opposed to telling a half truth came up as a dilemma for these nurses because of the family and patient’s ability to deal with the information. As stated above, information and education on the illness and progress of the illness for the patient were a way of helping the family to understand the terminal stage of the patient in a nonthreatening manner. In a study of hospice nurses and their definition of honesty, the nurses had a hard time defining honesty (Erichsen, Danielsson, & Friedrichsen, 2010). These nurses stated honesty was a basic human need, a way of behaving and a
quality in which they pursue compassion and empathy. These nurses also stated that openness and honesty were the basis of patient relationships in which trust and rapport were built with the client and family (Erichsen et al., 2010). Approaching the nurse relationship with the client and family requires openness and honesty from the beginning of care.

**Relationships in Hospice**

Support and open, honest communication from the nurse for the client and family were essential in hospice care. In addition support from staff for the nurse was important for the health and well-being of the nurses, facilitating their ability to care for clients. As stated in this research results, self-care is necessary when working with dying clients, which is only attainable with proper support from employers and colleagues. The concept of a psychological contract is one that describes the implicit expectations and promises assumed by the employer, patient, family, and colleagues (Jones & Sambrook, 2010). The psychological contract that exists between the employee and employer includes support and emotional outlet during collaborative meetings, where concerns can be voiced in a safe setting. This contract also exists on the colleague level in which coworkers keep each other in check emotionally. If one nurse notices the other struggle he or she may take the patient so the nurse on the edge of burnout may take a day off or just to lighten the load. Time to care was an element found in research done by the International Journal of Palliative Nursing on psychological contracts. This was also a subcategory of this research's findings related to
time management, in which a contract existed between the hospice nurses and their willingness to flex their schedule when a nurse was having a crisis with a patient which required more time and care.

**Further Research**

Recommendations for continued research related to hospice nursing are focusing on the families’ perspectives on the care provided. All participants discussed the challenges of families, and it is necessary to understand the family’s perspective on their experience with hospice to properly deal with this challenge for nursing care. Another aspect that was interesting for further investigation would be the case load each hospice nurse has to carry to meet the required “productivity” and how that affects care given and overall stress levels.
References


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Appendix A

Carroll College

Consent to Participate in a Study Related to Hospice Nursing

I have been invited to participate in a voluntary study by Carroll College Nursing student Shoshannah Seed. The purpose of the research is to gain understanding of the challenges of hospice nursing. I am aware that this research will be used to advance the understanding of the challenges of being a hospice nurse and there may be presentations and publications of this study.

If I choose to participate in this study I am willing to be audio taped by Shoshannah Seed for 30-60 minutes, in a confidential location. During the interview I will be asked to discuss my thoughts, feelings, and experiences with hospice nursing, and the coping mechanisms used during my hospice nursing experience. The risks associated with this study may include experiencing emotions when talking about hospice nursing. I may withdraw from this study at any time, which will remain confidential. Confidentiality will maintained throughout this study and my name and any identifying characteristics will not be disclosed. I am aware that at any point if I have questions I can call Shoshannah Seed at (406) 531-8718 or email at sseed@carroll.edu. Additional questions about the rights of human participants can be answered by the Chair of the Institutional Review Board, Jamie Dolan (406) 447-4969 or jdolan@carroll.edu.

I understand this consent and agree to participate in this study:

____________________________________________________                                __________________________
Participant Signature                                                                 Date

____________________________________________________                                __________________________
Researcher Signature                                                                Date
Appendix B

Sample Script

Tell me about the day to day challenges of your job as a hospice nurse.

Tell me about one of your most challenging experiences.

Tell me about how you cope with caring for individuals who are dying.

Tell me how you keep yourself healthy.

What do you recommend for nurses to decrease stress when working with individuals who are dying?

Have you seen burnout in your fellow hospice nurses?

Have you personally experienced burnout in hospice nursing?

How do you suggest preventing burnout? What helps you cope?

Tell me about the most rewarding aspects of hospice nursing.

Tell me about your experiences with the families of the dying client.

Tell me about any conflicts with coworkers, and how that affects your ability to care for your clients.