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Uncovering Meanings of Death, Trauma, and Loss as Experienced by Hospice Bereavement Coordinators: A Phenomenological Study

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Uncovering Meanings of Death, Trauma, and Loss as Experienced by Hospice

Bereavement Coordinators: A Phenomenological Study

by

Rochelle S. Clarke

A Dissertation Proposal Submitted to the

Graduate School of Humanities and Social Sciences of Nova Southeastern University

in Partial Fulfillment of the Requirements for the Degree

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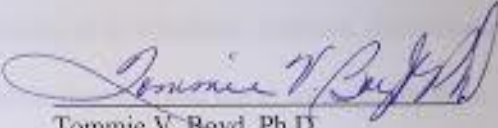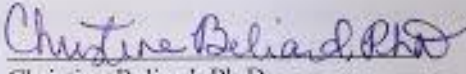
2015

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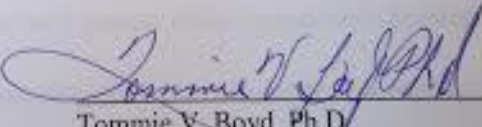
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Abstract

This study examined the experiences of Hospice Bereavement Coordinators (HBCs) and Hospice Chaplains working with grief narratives from patient-family units exhibiting signs of anticipatory or complicated grief. While a significant amount of research has been conducted on Hospice employees, no qualitative studies have examined the interpretation of meaning from employees whose primary role focused on the psychosocial-spiritual aspects of clients exhibiting anticipatory or complicated grief. The researcher identified shared meaning of death, trauma, and loss from six participants in the context of a high stress and high loss environment. This study's findings revealed ten central themes: Death is an earthly transition to immortality; Death is an intense progression; Trauma is an interpretive response to a bad experience; Trauma highlights quality of life; Loss is an adaptation to change; Loss highlights self-awareness about mortality; Cases impact views of death, trauma, and loss; Influences of spirituality; Stressful aspects of working in hospice settings; and Methods of coping.

Through this study, the researcher captured five elements of the shared phenomena: the conflicting nature of anticipatory or complicated grief with the participant's interpretation of death; the acknowledgement of loss as the next stage for survivors of the deceased; the instability patient-family units exhibiting anticipatory or complicated grief faced; the role of faith; and the proactive efforts of participants to create a balance between work and their personal life. These meanings contributed to the continued need for future qualitative studies whereby the lived experiences of Hospice employees could be expressed to assist with the development of structured training programs specific to the requirements outlined by the nature of their work.

CHAPTER I: INTRODUCTION

The bulk of literature surrounding Hospice employees focus on physicians, nurses and social workers. Currently there are no present studies centered on Hospice Bereavement Coordinators (HBCs) regarding their process of functioning in a high stress and high loss environment. Long term effects of exposure to death, trauma, and loss in Hospice employees reveal a need for stress reduction to decrease compassion fatigue and burnout in the field. Identifiable grief support and coping skills utilized to alleviate the stress of caring for dying patients and their family is missing from the literature on HBCs. This study is intended to capture the essence of meaning attributed to death, trauma, and loss to identify how these experiences manifest in the lives of HBCs. Their description of death, trauma, and loss may identify stressors, coping mechanisms, and compassion satisfaction which may lead to the implementation of continued training and support programs necessary to provide self-care.

Hospice Care

Medical settings focus on providing patients with quality care. For patients with a terminal condition there is the option of choosing to go under the care of Hospice. According to the National Hospice and Palliative Care Organization (NHPCO, 2014), Hospice care is considered to be the model for quality compassionate care for people terminally ill; care is tailored to meet the needs of the patient and their family. Annually more than 2.9 million deaths occur in the United States, affecting 8 to 10 million surviving immediate family members (Murray, Toth, & Clinkinbeard, 2005). In 2012, an estimated 1.5 to 1.6 million patients received Hospice services (NHPCO).

Hospice care involves medical supervision, emotional support, spiritual guidance, and pain management. In order for a patient to become Hospice appropriate a physician certifies that the patient has a prognosis of six months or less to live. In Hospice the focus of patient care shifts from typical curative measures to a focus on comfort care (NHPCO, 2014). In 2012, the average length of service increased from 69.1 days in 2011 to 71.8 days in 2013 (NHPCO). Of these patients more than 84.7 % were discharged due to death with the remaining 15.6% discharged because their condition stabilized or they were transferred to an inpatient unit (Caffrey, Sengupta, Moss, Harris-Kojetin, &Valverde, 2011). Palliative care or palliation of symptoms is employed to manage pain measures unlike curative measures aimed at eradication of the disease (Reese, 2013). With a focus on providing comfort during one's remaining days and to make legal, emotional, and spiritual preparations for death (Reese), patients and family members can better embrace the dignity of death (pain relief and comfort care).

Role of Interdisciplinary Team Members

The World Health Organization (WHO) defines a team as two or more people working interdependently toward a common goal. The team of professionals in Hospice consists of: physicians, nurses, pharmacists, social workers, chaplains, dieticians, bereavement coordinators, and volunteers (Parker-Oliver & Peck, 2006). The interdisciplinary team members provide their expertise and observation to deliver quality patient care (Parker-Oliver & Peck, 2006). All healthcare professionals make sure the patient's medical and supportive needs are met.

The role of the physician is to provide medical attention to the patient. A nurse provides onsite care for the patient while monitoring illness progression. Palliative physicians and pharmacists provide medications for pain management. Social workers assist the patient and family with questions they may have about the illness while supporting the family with end-of-life arrangements. Chaplains attend to the spiritual aspects of patient care, they provide the patient and family with spiritual concerns and guidance. Bereavement Coordinators engage in emotional support to facilitate open discussions of coping with the declining health of the patient and remembrance of the deceased to reduce anticipatory or complicated grief. Volunteers serve in multiple capacities from administrative support to assisting patients with household duties (i.e., grocery shopping) or daily chores (i.e., caring for pets). Collaboration among interdisciplinary team members certify management of end-of-life care to adhere to Hospice compliance and expectations of patient-family units.

Hospice Bereavement Coordinator

Hospice Bereavement Coordinators (HBCs) enter into the patient-family unit when situations become of great magnitude and when familial coping methods are ineffective. For the purpose of this study, coping methods are referred to as strategies utilized to reduce pain, distress, suffering, and support emotional adjustment. There are multiple variables associated with end-of-life that impact a person's emotional reaction. For this reason, HBCs provide grief support for patients and family members individually, collectively, and within group settings. According to Caffrey et al. (2011) of the 1.5 to 1.6 million people under the care of Hospice, 83.6% of patient-family units receive bereavement services.

Hospice Bereavement Coordinators are mental health professionals from fields of social work, mental health counseling, and marriage and family therapy. According to the Degree Directory, HBCs typically complete graduate course work to include classes in counseling techniques, theory, ethics, psychotherapy, and group therapy, (2014). In addition, most states require licensure to practice in the profession followed by a two year post-graduate clinical externship. The outline of course work and licensure seek to provide experience in the field while post-graduate external practicums or clinical externships afford experiential exposure.

Within the curriculum, an element that is often neglected is self-care. The term self-care denotes an ability to develop skills that maintain optimal psychosocial functioning. Hospice Bereavement Coordinators are constantly faced with situations that disrupt emotional balance. Challenges and stressors include frequent encounters with grief from clients and their families as well as witnessing extreme physical and emotional pain. These experiences often result in transference of physical and emotional exhaustion (Alkema, Linton, & Daves, 2008). Factors such as experiences with personal loss, the nature of the loss, and length of their relationship with hospice patients and families shape their experience of a patient's death (Quinn-Lee, Olson-McBride, & Unterberger, 2014). The constant exposure to death, trauma, and loss in Hospice settings can leave employees overwhelmed with the duties of their job. Without support, Hospice employees may find themselves in situations where they are unable to function. Despite this, health care providers do not receive adequate training and instruction to process their emotionality with caring for the dying (Eagle, Creel, & Alexandrov, 2012). Furthermore,

feelings of inadequacy, job-related stress, burnout, and increased attrition are all associated with unresolved health care providers' grief (Eagle et al., 2012).

Hospice Setting

There are nation-wide Hospice organizations established in America. This study will be conducted at a faith-based Hospice in South Florida. They provide end-of-life care to patients and families in Miami-Dade, Broward, and Monroe counties. Their mission is to provide healthcare and services to those in need, minimize human suffering, assist people to wholeness, and nurture an awareness of their relationship with God. In Hospice settings, professional staff is on call 24 hours a day, seven days a week to provide support specific to the needs of each patient-family unit.

This setting is appropriate to conduct this study as it is a Hospice organization which employs HBCs. As an aside, social workers and HBCs at this organization have the same type of academic background, however; the social worker's role is to provide community support and after death arrangements whereas the HBCs primary role is to work with complicated grief cases. Programs are developed to support bereavement for patient-family units. Their total quality patient and family care incorporates pet therapy, music therapy, spiritual guidance, and support to reduce pain, stress, anxiety, depression, and loneliness. In addition, HBCs lead groups in the community to foster partnerships with local agencies designed to meet the needs and demands of the patient-family unit. To ensure children develop coping skills, there is a bereavement camp held twice a year to facilitate the bereavement process. Numerous programs are developed at this organization to support patients, families, and the community.

Self of the Researcher

The researcher, a Medical Family Therapist, is currently employed as a HBC at Catholic Hospice. Medical family therapy is distinguished by its conscious attention to medical illness and its role in the personal life of the patient and the interpersonal life of the family (McDaniel, Hepworth, & Doherty, 1992). The researcher encountered difficulty processing the emotional responses of the job. This study was prompted by the researcher's pursuit of gathering research studies to learn about coping skills and processes Hospice employees utilize. The researcher found literature on end-of-life care and long term effects of working in Hospice settings, but little guidance on methods to process multiple grief narratives and ways to prepare for losing a patient.

The researcher became curious about the way other HBCs managed the stress of the job. Questions began to arise. What were some of the challenges the other HBCs faced? How were they able to process their experiences of grief narratives? How do they respond to the death of their patient, do they notice different responses? Was there specific training they received academically, on the job, or was experience the guiding factor? How would they describe their emotionality? As Whitebird, Asche, Thompson, Rossom, and Heinrich (2013) discussed, "The stress of working with so many people and their families in life's most difficult transition is often considered a pivotal factor in burnout in the profession" (p. 1534). Their research suggested people working in Hospice settings experience high stress which leads to high employee turnover. The researcher was led to conduct this study as a need evolved to understand how HBCs were able to process narratives of death and dying. As previous studies utilized surveys to capture the

stress Hospice employees face, this research seeks to capture the words HBCs use to describe working with patient-family units experiencing anticipatory or complicated grief.

Statement of the Problem

The fear of death is a universal phobia experienced by humans with societal preference strongly advocating the preservation of life (Peters, Cant, Payne, O'Connor, McDermott, Hood, Morphet, and Shimoinaba, 2013). Exposure to the processes accompanied by death generates an individual's consciousness of their own mortality giving rise to anxiety (Peters et al., 2013). HBCs are engaged in daily narratives of death and dying from a first person account with the patient and a second person account of the difficulty that lies ahead from the family members as they adjust to the thought of living without their loved one. Healthcare professionals are faced with the task of delivering the daunting message to a patient of their terminal disease progression. Gazelle (2007) researched the effects of physician's attitudes and dilemmas surrounding hospice care. The study discussed factors for delayed referrals into hospice,

> . . . The American Society of Clinical Oncology acknowledged that many Oncologists and other physicians regard the death of a patient as a professional failure. Many also fear that they will destroy their patients' hope, which physicians may believe lies only in efforts to increase the quantity rather than quality of life. . . . little training in the compassionate discussion of bad news. (Gazelle, 2007, p. 322).

The study found a need for physicians to become more familiar with the process of hospice care and work to overcome barriers in speaking frankly with patients about the progression of their illness (Gazelle, 2007).

Hospice Bereavement Coordinators listen to the emotions revealed by each patient and their family experiencing anticipatory or complicated grief. The narratives are depicted with raw physical, emotional, and psychological expressions of despair. The HBC delicately maneuvers in and out of the patient-family system in order to facilitate the construction of new meaning out of the grief stricken reality of death. The HBC also develops an understanding and meaning from the experiences they are exposed to during the therapeutic process. Hospice Bereavement Coordinators must create alternative realities that incorporate the meaning of their patients' lives, as well as the turmoil their death creates in the lives of their family.

At times, the terms grief and bereavement evoke images of sadness, despair, and loneliness (Dutton & Zisook, 2005). Dutton and Zisook (2005) conducted research on widows and widowers 2 months after their spouses passed away to observe bereavement processes. The researchers noted that although bereavement can be devastating it also marks, ". . . a time of remarkable growth and resilience. . ." (p. 878). The researchers suggested a need to identify elements of successful adaption to bereavement as a way to design and implement new grief interventions (Dutton and Zisook, 2005). The HBC synthesizes narratives and engages in therapeutic conversations to evoke the process of healing to begin in grief stricken individuals. Few discussions are prompted to understand the impact these experiences and narratives of death, trauma, and loss have on HBCs. How are they able to process their emotions? How would they describe their challenges?

How do they find support? Are there specific ways they manage the stress of their job? These are relevant questions that have not been addressed in literature.

Therapeutic Dialogue

Therapeutic dialogue during this sensitive time attempts to provide solace to patient-family units experiencing grief. This process can become both stressful and emotionally draining for HBCs. As Becvar (2003) noted, "Accordingly, in addition to the normal stresses associated with work in the health and mental health arena, there are many other burdens and challenges that are unique to working with dying or grieving persons" (p. 471). Becvar identified various stressors that impact Hospice care workers; it is not at all unusual to be preoccupied with or haunted by the pain clients may be experiencing. Stressors were identified as constant exposure to death, inadequate time with dying patients, and a growing workload (Becvar, 2003).

Statistics revealed 83.6% of patient-family units use bereavement services (Caffrey et al., 2011) although significant, the number of services offered to HBCs to cope and manage through the stressors of the job is not revealed in the literature. Additional stressors for Hospice care workers included inadequate coping with their own emotional response to the dying, increasing number of deaths, communication difficulties with dying patients and families, feelings of grief, depression, and guilt (Slocum-Gori, Hemsworth, Chan, Carson, & Kazajian, 2011). A response to the stress experienced by Hospice care workers is termed compassion fatigue.

Compassion Fatigue

Compassion fatigue relates to the emotional cost of caring for others whereby the professional abandons his/her work with traumatized victims (Slocum-Gori et al., 2011).

Compassion fatigue is typically portrayed as a stress response that emerges without warning and includes a sense of helplessness, isolation, and confusion. As a way to identify factors that may contribute to compassion fatigue and create beneficial training programs to proactively detect issues and concerns, studies need to evaluate the need for self-care. Melvin (2012) researched the prevalence of professional compassion fatigue (PCF) among hospice and palliative nurses ". . . as well as the nature of its effects and any coping strategies that nurses adopt" (p. 606). Participants engaged in interviews using semi-structured questions to understand the effects of working with Hospice patients over an extended period of time. Melvin (2012) termed professional compassion fatigue, burnout, and loss as ". . . the cumulative physical and emotional effects of providing care over extended periods of time" (p. 606). Melvin found biopsychosocial consequences associated with professional compassion fatigue (PCF). His research recommended the development of support strategies for nurses as well as,

> . . . scholarly work in the area of PCF would add to the body of knowledge of this phenomenon and increase the understanding of the effects of repeated exposure to patient deaths; early identification needs to be made . . . and strategies must be developed to better assist distressed nurses. (p. 611)

This study supported research indicating stress among nurses providing hospice and palliative care. Melvin (2012) found boundary setting as a healthy coping strategy, ". . . personal strategies for coping with PCF included getting adequate sleep, good nutrition, regular exercise, and relaxation. . . . Engaging in non-work activities often rejuvenates and restores a person's energy commitment and focus" (p. 610). Melvin recommended implementation of strategies to assist nurses' exposure to ongoing deaths, additional

scholarly work addressing the effects of repeated exposure to patient deaths, and a need for early strategies to assist distressed nurses. The creation of a program that outlines signs to look for and ways to combat compassion fatigue may help to reduce feelings of stress associated with caring for dying patients. If not attended to, compassion fatigue may lead to depression and stress-related illness (Slocum-Gori et al.).

Compassion Satisfaction

Conversely, compassion satisfaction denotes educational rewards of caring for others in a health care context whereby clinicians feel a sense of return or incentive by seeing a change for the better in their patients and families (Slocum-Gori et al., 2011). There is a need to reduce stress levels for Hospice employees, however, tools for assessment are typically via surveys, which limits personal experience. Diamond, Llewelyn, Relf, and Bruce's (2012) study on helpful and unhelpful support for the bereaved identified a need for more qualitative types of research to detail information on the sequencing of events. As Wilder, Parker-Oliver, Demiris, and Washington (2008) discussed,

> Decreased emotional quality of life is likely partially attributable to impending loss of a loved one and the probable deteriorating condition of the patient. To some extent, this may be an unavoidable part of the grieving process that begins at patient's diagnosis with a terminal prognosis; providing emotional support to the patient has also been reported to be one of the most difficult care giving tasks. (p. 324)

The study found emotional quality of life as another area of focus for Hospice providers that may not be receiving as much attention and support as could be helpful during the dying process and bereavement period.

Johnston and Smith (2005) conducted a phenomenological study with twenty two registered nurses and twenty two patients to identify if there was an expectation from patients and palliative nurses to be an 'expert' in the delivery of care facing the terminally ill. Johnston and Smith (2005) identified life threatening illness as cancer, neurological, cardiac and/or respiratory disease as they have implications for physical, social psychological, and spiritual health for patients and their family.

> This study was original in that it explored palliative nursing from the perspective of patients and nurses working in both hospices and hospitals. Rarely have palliative care patients been asked about their opinions of their care and never before about their perceptions of an 'expert palliative care nurse'. (Johnston and Smith, 2005, p. 708).

Their findings suggested a need for mandatory interpersonal skills training for palliative care nurses as part of postgraduate academic programs or continuing education courses as ". . . patients perceived that expert palliative nursing care consisted of effective interpersonal skills and caring skills, and that the nurse should meet their needs by helping them, 'being there' for them, providing them with emotional support, being someone to talk to, providing comfort and, most importantly, spending time with them" (p. 707). Psychosocial aspects revealed differences between the nurse and the patient as the patients experience was without respite and consumed with fears about their

prognosis. Nurses tended to have definitive views of a good quality of live and a good death as influenced by their professional education and experience.

Stress that staff experience when caring for patients and families is often associated with a lack of emotional support and difficulty dealing with the suffering at the end-of-life (Whitebird et al., 2013). Running, Woodward, Girard (2008) conducted a study of hospice nurses to examine benefits of including rituals and healing practices for hospice employees. Weekly gatherings were initiated to assist hospice staff share with each other the losses they experienced. Their research found ". . . not all hospice nurses are being provided an opportunity to practice in these important aspects of grieving rituals that might serve to increase their job satisfaction as well as decrease their risk for compassion fatigue or occupational burnout" (Running, et al., 2008, p. 306). There may be benefits to creating programs specifically targeted to focus on self-care of HBCs. People entering the Hospice field need to understand the social constructions surrounding death and dying in America. This cultural competence will allow them to develop unique strategies to normalize this inevitable process for patient-family units as well as themselves.

The absence of emotional quality of life translates into a lack of support for HBCs to process trauma experienced through death narratives. As Rolland (1994) found, "Therapists working with terminally ill patients and families should have professional peer support to discuss their feelings of sadness, loss, and helplessness" (p. 249). The absence of protective factors such as organizational support, supervisory support, and education on early signs of burnout could lead to the dehumanization of the dying process as a means to cope. There is a need to conduct qualitative interviews with employees

working in Hospice settings to gain an experiential understanding of interpretations and perceptions derived from working with the dying and their family.

Purpose of the Study

Research has not been conducted on HBCs and their ability to process anticipatory or complicated grief narratives. The impact of professional quality of life on patient care can be significant in identifying favorable and unfavorable work environments (Smart et al., 2014). Neimeyer, Baldwin, and Gillies (2006) conducted a study utilizing attachment theory and constructivist concepts of bereavement to assess the relationship between coping and meaning reconstruction following the death of a loved one. The study consisted of five hundred and six young adults in the first two years of experiencing a variety of losses. A survey was completed to measure the strength of their attachment to the deceased and identify complicated grief symptomatology. Neimeyer et al., (2006) found,

> . . . high levels of meaning making consistently predicted better grief outcomes
> during the first two years of bereavement for this young adult sample, whereas
> high levels of post-loss attachment to the deceased were associated with more
> complicated grief symptoms, at least under conditions of low sense-making.
> (p. 732).

Their research found a need to develop operational meaning making processes as, ". . . continuing bonds appear to interact with meaning making in response to loss, such that those survivors who are able to make sense of the loss in personally meaningful terms experience fewer symptoms of complicated grief" (p. 735). Their research highlighted

the benefits of incorporating memories of the deceased into the daily lives of the

bereaved as a useful technique to reduce symptoms of complicated grief.

Hospice Bereavement Coordinators enter into a system by listening to a patient

with a terminal diagnosis express fear and anxiety about dying or witnessing a family

who spends their time arguing about their loved one's impending death. As Finucane

(1999) posits:

> Death will remain difficult. First is the widespread and deeply held desire not to
>
> be dead, this not only existential angst, or the dread of ultimate insignificance, it
>
> is also a struggle to avoid annihilation. Second is medicines inability to predict
>
> the future and give a reliable prognosis about when death will come. (p. 1638)

The aim of this research is to better understand the meanings and experiences HBCs

encounter working in Hospice settings. Scenarios of a family's incessant preoccupation

with the patient's terminal diagnosis to acknowledge their loved one's life or processing

the loss of a loved one with multiple family members are daily encounters for HBCs. For

the purpose of this qualitative phenomenological study, the research question is: "What

meaning do HBCs ascribe to their experiences of death, trauma, and loss working in

hospice settings with patient-family units exhibiting anticipatory or complicated grief?"

This study seeks to examine the interpretation of death among HBCs in a Hospice faith-

based organization in South Florida to determine central themes, if any. Uncovering the

experience of death through the lived experiences of HBCs will serve as a guide for

designing and implementing training programs and continued education to support

Hospice employees.

<center>**CHAPTER II: LITERATURE REVIEW**</center>

Multiple factors are considered in Hospice settings to ensure optimal quality of care is delivered to patient-family units. The clinical team diligently works to ensure the medical and psychosocial needs of the patient and family are met. In an environment where terminal illness creates heightened emotions within families the clinical caregivers become a part of the system as they seek to lower anxiety and stress. Optimal service delivery requires an awareness of the biopsychosocial-spiritual factors that impact the clinical team, specifically HBCs who listen to unresolved narratives stemming from anticipatory or complicated grief.

Literature outlined in this chapter suggest a need for more qualitative studies to understand the lived experience of people delivering end-of-life care. Considerable increases in compassion fatigue and burnout occur when Hospice team members are unable to resolve issues surrounding the impact of a patient's death on their lives. This research will serve to capture the phenomena of death, trauma, and loss which may lead to specific challenges HBCs face. A systemic approach will guide the researcher to identify themes, if any, between HBCs and others, whose primary responsibility is to process grief narratives. As interdisciplinary teams are customary in Hospice settings a systems approach leads the researcher to observe all factors surrounding the delivery of services including the impact anticipatory or complicated grief may have on those who deliver psychosocial support.

<center>**Hospice Interdisciplinary Teams**</center>

In order to meet the needs of patients and their family, Hospice consists of interdisciplinary teams to ensure the collaboration of quality patient care. According to

the NHPCO (2014), the Hospice team typically consists of the patient's personal physician, a Hospice physician or medical director, nurses, home health aides, social workers, clergy or other counselors, trained volunteers, as well as speech, physical, and occupational therapists. The interdisciplinary team promotes a holistic model of care whereby treatment is focused not on curative treatment but on palliative care, aimed at promoting quality of life during death and dying (Reese, 2013). As Boyd, Watters, Canfield, and Nativ (2011) highlighted, "Each member of the team brings a particular understanding and provides a unique solution to address the patient's emotional and physical pain" (p. 28).

In addition to the Hospice interdisciplinary team the patient's family may also serve as a resource of support. Spouses, partners, children, siblings, parents, and other relatives or friends oftentimes serve as caregivers as they administer medication, evaluate the patient's symptoms, and deliver daily personal care and assistance to the patient (Wilder et al., 2008). They also provide emotional support to the patient while maintaining additional functions such as employment inside or outside of the home and may take care of financial matters regarding patient care.

The interdisciplinary team delivers care in compliance with four foundations of Hospice care: holistic care, self-determination, comfort care, and development continuum (Parker-Oliver & Peck, 2006). Holistic care recognizes the patient and his or her family as a complete unit (Parker-Oliver & Peck). Self-determination care incorporates the patient and family's values as governing agents to guide the delivery of services (Parker-Oliver & Peck). Comfort care focuses on providing quality of life to patients and ensures proper pain management (Parker-Oliver & Peck). Comfort measures are given to reduce

physical and mental pain the patient may experience (Parker-Oliver & Peck).

Development continuum delivers education and discussion whereby the patient and

family acknowledge death as the final stage of development (Parker-Oliver & Peck). The

complexities of the Hospice interdisciplinary team allow the continuum of care to operate

from a biopsychosocial and spiritual system.

Biopsychosocial-Spiritual Model

The term biopsychosocial and spiritual system refers to the idea that all problems

are at once biological, psychological, and sociological with an interlay of spirituality

(McDaniel et al., 1992). George Engel (1977) developed the biopsychosocial model in

order to understand the determinants of disease and provide a rational treatment option

for patients clinicians must take into account. According to Engel (1977), ". . . the

patient the social context in which he lives, and the complementary system devised by

society to deal with the disruptive effects of illness, that is, the physician's role and the

health care system. This requires the biopsychosocial model," (p. 132). These domains

act within the concept of quality of life as they are interrelated whereas that one domain

may affect quality of life in another area, thus, each is a unique contributor to the other

(Wilder et al., 2008).

There are biological, psychological, sociological and spiritual aspects associated

with making the decision to enroll in Hospice. As Engel (1977) noted, "The boundaries

between health and disease, between well and sick, are far from clear and never will be

clear, for they are diffused by cultural, social, and psychological considerations,"

(p. 132). Patients and families realize the fatality of the illness and begin to process

end-of-life care. According to Borrello-Carrió, Suchman, and Epstein (2004),

The late George Engel believed that to understand and respond adequately to

patients' suffering—and to give them a sense of being understood—clinicians

must attend simultaneously to the biological, psychological, and social

dimensions of illness. . . . His new model came to be known as the

biopsychosocial model. (p. 576)

Patient's religious or spiritual beliefs may affect treatment and perceptions about the

illness. Onarecker and Sterling (as cited by Katerndabl, 2008) proposed that the

biopsychosocial model be revised to include spirituality. Associations between

biopsychosocial symptoms and spiritual factors suggest that spiritual symptoms may act

synergistically with these other symptom dimensions to affect health (Katerndabl). The

biopsychosocial and spiritual systems are influenced in and between each other. Utilizing

a biopsychosocial-spiritual therapeutic approach creates understanding between the

dynamic factors each plays on influencing the patient, family, and their relation to the

illness.

Biological

The biological decline of the patient may create uncertainty within the patient and

family as the illness progresses. Neimeyer et al. (2014) posit,

. . . although grief and mourning may be universal and biological, both the story

of the death itself and our changed relationship to the deceased are personally

narrated, socially shared, and expressed in compliance with or contradiction to

widely varying communal rules. (p. 486)

Physically, the body starts to slow down and the patient with a terminal diagnosis will

begin to lose bodily functions (Leming & Dickinson, 2010). Although terminal illness

can be associated with a specific condition, healthcare professionals must be knowledgeable and sensitive in the initial explanation of the illness. While listening to the description of the illness and its effect on the body the patient and family develop meanings associated with the illness.

Hospice Bereavement Coordinators observe the nature of the patient and family's response to the illness in order to gather the familial description. This initial observation can be a key component in maintaining stability within the family and reducing anxiety. According to Goolishian and Anderson (1994), "The therapist is an expert in the management of the communicative process and through the conversation of the conversation mutually evolves and invites new meanings" (p. 536). This allows the HBC to become skilled in maintaining conversations which generate manageable dialogue about the process of dying (Goolishian & Anderson, 1994).

Psychological

Psychologically a patient and family process the adjustment of the loss of life. Rolland (1994) noted, "A family must learn to live in limbo and grieve for the ambiguities they must endure over the long term" (p. 175). For the HBC, Rolland posits, "Professional involvement with illness and loss is usually an added strain, particularly with certain patients or at different junctures of our own individual and family life cycles" (p. 280). As the patient and family resolve issues around terminal illness and dying with HBCs, they become a part of the system. The comfort and effectiveness in working with families coping with illness is dependent on the HBCs ability to accept vulnerability, mortality, and the inevitable loss of loved ones (Rolland, 1994).

Sociological

There are several social factors to consider when working with terminally ill patients and their family. According to Rolland (1994), "Making peace with self, family and world is a fundamental task in coping with threatened loss, especially in the terminal phase. Several kinds of beliefs complicate this normative process" (p. 193). Hospice Bereavement Coordinators learn about unresolved issues and guilt between the patient and family members. Family beliefs about illness and rituals associated with dying contribute to social implications of the illness. Hospice Bereavement Coordinators may consider social constructions of the illness and work within the system to facilitate the process of loss.

The HBCs also adjusts to social stigmas of working with dying patients and death. Rolland (1994) noted, "Therapists working with terminally ill patients and families should have professional peer support to discuss their feelings of sadness, loss, and helplessness" (p. 249). Social support systems allow HBCs to process loss.

Spiritual

Religion and spirituality play an important role in facilitating the conversation about illness and death with patients and families. Families may or may not have rituals associated with end-of-life care. Hospice Bereavement Coordinators can help incorporate rituals into their lives if requested. Rolland (1994) noted, "Some families may be unaware that they have special beliefs or practices, and the process of selecting desired rituals helps them consider what could be comforting" (p. 246). Religion provides patients and families with a guide for mourning and burials.

Hospice Bereavement Coordinators working in a religious setting may rely on spiritual resources that may be provided. They may also develop rituals for saying good-bye to patients. Rolland (1994) highlighted,

> Working with families experiencing loss changes the therapeutic relationship. Therapists and families share some of the intense emotions surrounding loss, and usually develop deep respect for one another. As families can use the experience of loss to grow closer, more honest, and more appreciative of life, so can therapists respond to these extraordinary challenges. (p. 249)

Hospice Bereavement Coordinators may choose to attend patient rituals such as funerals or memorial services to develop closure.

A Systems Approach

A systemic approach to loss ". . . can be viewed as the transactional process involving the dying and deceased with the survivors in a shared life cycle that acknowledges both the finality of death and the continuity of life" (Walsh & McGoldrick, 2004, p. 3). Through a systemic lens the experiences an individual encounters can be generated and processed in a way that creates new meaning that changes a problematic experience. According to Flemons (1991), "A systemic approach to therapy can thus be described in terms of its sensitivity to layered networks of premises and patterns of circular interaction, within and between ideas and people" (p. 16). Humans can be defined as language-generating, meaning-generating systems engaged in an activity that is inter-subjective and recursive (Anderson & Goolishian, 1988).

Through language the HBC and the patient are no longer separate from each other as the narration of the illness provides experiential context. Keeney (1983) highlighted, "Rather than identifying therapist and client as separate agents who act upon each other, cybernetics looks for patterns that connect both components through a feedback structure" (p. 111). There is a reciprocal type of relationship forming by which the HBC is being impacted by the patient's lived experience and the patient is sharing in a transformation. The lines of separation between the HBC and the patient become blurred as the dialogical experience creates new realities by expanding on the description. Flemons (1991) noted, ". . . the informational process of perception, communication, learning evolution, and so on— is a function not only of difference, but also of difference between differences . . ." (p. 22). The idea is that an individual can have an experience and then through conversation be transformed into taking a new stance.

Varela, Rosch, and Thompson (1992) discussed, ". . . new sciences of mind need to enlarge their horizon to encompass both lived human experience and the possibilities for transformation inherent in human experience" (p. xv). Charles-Edwards (2009) conducted a study on managerial expectations for managing bereavement with employees. The study reviewed the importance of the workplace culture's role on how bereaved or terminally ill people manage their grief. The study looked at the critical role bereavement plays in healthcare both as an independent management for counselors and occupational health staff and within management. The role it plays from a management perspective ". . . exclusively as a specialist area, managers and others can be discouraged and feel disabled from intelligently supporting the staff with whom they work" (p. 420). The study identified a number of reasons why managing death is difficult for managers

and stressed the importance bereavement measures have on both task and person centered influences. As Charles-Edwards (2009) highlighted, "Bereavement can shake the foundations of their lives, so it is hardly surprising that the workplace can provide a significant element of stability and familiarity, as well as at times discomfort, amidst what can be an unpredictably fast changing landscape" (p. 426). The study suggested a ". . . proactive and comprehensive approach that is needed for the sake of both the people involved and the wider well-being of the organization" (p. 435). Creating a bereavement process to provide immediate support and reactions to the impact of working with terminally ill patients allows the organization to ensure its company's competence and reliability of written material to support employees with issues of death and bereavement. A more proactive approach is needed to address needs of the bereaved.

Listening to multiple narratives about anticipatory or complicated grief allows a person to witness transformation within the therapeutic context. Slocum-Gori, Hemsworth, Chan, Carson, Kazanjian (2011) conducted a study to understand the relationship between compassion satisfaction, compassion fatigue, and burnout within hospice and palliative care nurses. Slocum-Gori et al. (2011) conducted a nationally administered survey in Canada to understand ". . . those factors that foster a positive response in the face of constant exposure to grief and bereavement. . ." (p. 172). They surveyed 630 Hospice employees and found that compassion fatigue was identified as unique to "helping professionals" whereby without warning employees feel a sense of helplessness, isolation, and confusion which leads to depression and stress. Their findings suggest a need for resources and decisions directed towards developing education and training programs for hospice and palliative workers to maximize compassion satisfaction

and minimize compassion fatigue and burnout. "Despite awareness of the stress on oncologists and oncology nurses, training programs are lacking the curriculum elements to teach physicians and nurses how to cope with hospice and palliative care (HPC), including the psycho-social needs of the dying patients and their families. Slocum-Gori et al., (2011) "In addition, how program development may need to change to meet the individual and organizational cultural needs of the HPC workforce warrants further investigation" (p. 177). Solcum-Gori et al. (2011) also found self-care interventions as a resolution to reducing levels of compassion fatigue and increasing compassion satisfaction in Hospice employees. Walsh, Breslin, Curry, Foreman & McCormack (2013) conducted a study in a hospital setting to gather information about starting bereavement care services. Their research found hospital employees positively responded the bereavement care services. "The study suggests that some staff positively rate annual programs of training activities, memorial services, and public lectures" (Walsh, et al., 2013, p. 565).

Instances where HBCs were given an outlet to process meaning they derive from listening to death narratives would likely limit biopsychosocial impairments. The problem is formed from an inability to discuss traumatic events which may impact their lives. Research conducted by Smart et al. (2014) focused on compassion fatigue was compared to vicarious, traumatization, secondary traumatic stress, and burnout among healthcare providers in the United States. The study sought to add to what is known about compassion fatigue and compassion satisfaction (Smart et al., 2014). Compassion satisfaction was described as the ability to receive gratification from care giving, including positive aspects of work that nourished a clinician (Smart et al., 2014).

Self-administered surveys were given to 139 healthcare professionals. The study concluded work schedules and a culture of supporting health self-care habits can be considered as a strategy to decrease compassion fatigue (Smart et al., 2014).

There is a mutual vulnerability associated with candid discussions of grief and loss. Wright, Zhang, Ray, Mack, Trice, Balboni, Mitchell, Jackson, Block, Maciejewski, & Prigerson (2008) conducted a multisite longitudinal study of patients with advanced cancer and their caregivers to determine whether end-of-life discussions with physicians are associated with fewer aggressive interventions by patients. "To date, however, research has not examined whether these discussions are associated with patients' psychological distress or medical care near death. Without this information physicians cannot weigh the risks and benefits of end-of-life discussions" (p. 1665). Wright et al., (2008) noted "Physicians also often avoid these conversations, communicate euphemistically, are overly optimistic, or delay discussions until patients are close to death, perhaps because their own feelings of failure or loss" (p. 1672). The researchers found that end-of-life discussions are associated with less aggressive medical care near death and earlier hospice referrals. "Given the adverse outcomes associated with not having end-of-life discussions, there appears to be a need to increase the frequency of these conversations. By acknowledging that death is near, patients, caregivers, and physicians can focus on clarifying patients' priorities and improving pain and symptom management" (p. 1672). Additionally, Rabow, Hauser, and Adams (2014) discussed the experience of caring for loved ones as they approach death as one of deep fulfillment or significant trauma. Their research suggested the importance of building a relationship with the physician whereby conversations about death of the patient could be spoken

openly so that patient and family members could begin to prepare as best they can (Rabow et al., 2014).

Systemic Patient Perspective

The biopsychosocial-spiritual approach to delivering quality patient care observes the patient in connection with internal and external factors. Acting as a single unit the interdisciplinary team functions to analyze the role each person plays in the delivery of quality patient care. This creates a systemic approach to viewing the healthcare delivery of the patient. The foundation of a systemic or systems approach provides a sophisticated way to analyze and work with circular interaction processes, boundaries, and beliefs in the complex system involving a patient, their family, medical providers, and a variety of other groups that work collaboratively on the interdisciplinary team (McDaniel et al., 1992).

Borrell-Carrió, Suchman, and Epstein (2004) conducted a study to review George Engel's biopsychosocial model twenty-five years later. Borrell-Carrió et al., (2004) ". . . considered emergent properties that would be highly dependent on the persons involved and the initial conditions with which they were presented. . ." (p. 577). The researchers sought to understand the systemic value of George Engels' biopsychosocial model.

> Patient-centered, relationship-centered, and client-centered approaches propose that arriving at a correct biomedical diagnosis is only part of the clinician's task; they also insist on interpreting illness and health from an intersubjective perspective by giving the patient space to articulate his or her concerns, finding out about the patient's expectations, and exhorting the health professional to show the patient a human face. (Borrell-Carrió et al., 2004, p. 578).

The researchers suggested the biopsychosocial model as a recursive dialogic model whereby ". . . the reality of each person is not just interpreted by the physician, but actually created and recreated through dialogue" (p. 578). The patient and their illness becomes ". . . simultaneously a statement about the patient's life, the here-and-now enactment of his life trajectory, and data upon which to formulate a diagnosis and treatment plan" (p. 578). Researchers noted "George Engel's most enduring contribution was to broaden the scope of the clinician's gaze. His biopsychosocial model was a call to change our way of understanding the patient and to expand the domain of medical knowledge to address the needs of each patients. It is perhaps the transformation of the way illness, suffering, and healing are viewed that may be Engel's most durable contribution (p. 581).

Within the contextual frame of the systems approach the patient is viewed in totality, wholeness. As patient assessments are written they are inclusive of the multiple roles the patient plays, the role the illness plays, the impact and interpretation the illness holds to the patient and their family. A patient's culture is also assessed for decisions about end-of-life care and a belief in death. We may not assume that any cultural group is homogeneous; there is wide variability between members of a group in terms of income, education, employment, geographic region, and country of origin (Reese, 2013). Therefore, it is up to the interdisciplinary team to work collaboratively to meet the patient needs and gather information about the interpretation of the illness and the expectation the family has of Hospice.

Medical Family Therapy

As previously mentioned, George Engel (as cited by Borrello-Carrió, Suchman, and Epstein, 2004), provided a theoretical framework for the biopsychosocial model which incorporates the interconnectedness between the body and mind. The biopsychosocial model utilizes the perception of the illness through the expressed experience of the patient and family.   This "dialogic" model suggests that the reality of each person is not just interpreted by the physician, but actually created and recreated through dialogue (Borrello-Carrió, Suchman, & Epstein, 2004). As Doherty et al. (1994) noted,

> We introduce the term medical family therapy to refer to biopsychosocial treatment of individuals and families who are dealing with medical problems. As we conceptualize it, medical family therapy works from a biopsychosocial systems model and actively encourages collaboration between therapists and other health professionals. (p. 2)

This model of care works in conjunction with the fundamental tenants of Hospice as it views the patient systemically and holistically.

Medical family therapists are trained to work within complex medical settings to analyze the process patient and families encounter as the illness progresses. As Boyd and Watters (2012) highlighted, ". . . a medical family therapist is envisioned in the context of such interdisciplinary collaboration, working alongside and in collaboration with medical professionals, clinical strategies reflect the medical context of medical family therapy practice" (p. 245). They become part of the team of healthcare providers as well as part of the family's team. Strategically they can assist the family with communication and

coping mechanisms. The medical family therapist identifies the strengths of the family in order to help them work collaboratively.

Social Constructs of Grief

If there is to be a discussion about anticipatory or complicated grief it is to acknowledge the reality that a future absent of the person can trigger multiple responses. According to Neimeyer (2005-2006) symptoms of complicated grief are, ". . . reflections of an atypical grief process whose frequency differs notably from more common symptoms of normal grieving" (p. 48). Patients living with a life-threatening illness focus on various aspects of their future, for example, the effects and progression of the illness, treatment procedures, the process of dying, their death, and life after their death (Fulton et al., 1996). The patients loved ones may perceive their absence as an impending death of the individual which is experienced as a threat of injury and abandonment. Prigerson and Jacobs (2007) researched the effects of bereavement with a widow for two years to examine distinctions between symptoms and outcomes of uncomplicated and complicated grief. The researchers defined bereavement as ". . . associated with declines in health, inappropriate health service use, and increased risk of death" (p. 1369). The researchers sought to understand the role physicians play with bereaved patients. The study recognized loss through death as common and an extremely stressful experience whereby bereavement heightens a person's risk of depressive symptoms.

Despite the frequency with which physicians encounter bereaved patients,

medical training offers little guidance in the provision of bereavement ("after")

care. Physicians are often uncertain of how to distinguish between normal and

pathological grief reactions in their bereaved patients, and how to manage their

health care. (Prigerson and Jacobs, 2007, p. 1369).

The study yielded a need for physicians to engage in bereavement care as patients

continue to come to the physician following the death of their loved one. "Enhanced

efforts to discuss the medical decisions and care leading up to the patient's final moments

may assist both surviving family members and physicians in attaining a greater sense of

closure" (p. 1375). Prigerson and Jacobs posit, "Empathetic 'aftercare' for bereaved

patients demonstrates the physician's respect for the deceased and concern for surviving

family members. It may soften the psychological blow of losing a loved one and reduce

the family's sense of abandonment by the health care system" (p. 1375). According to

Cade and O'Hanlon (1993), "Where there is more than one frame for interpreting any

experience, there are a number of ways, sometimes conflicting, that we might interpret

our experience . . ." (p. 48). While the individual and their loved ones process the

impending death they are faced with a number of socially defined behaviors that are part

of the dying role (Fulton et al., 1996).

A fundamental level of understanding stems from familial interpretation, cultural

assumptions, and religious influences surrounding death, dying, and grief. According to

Abercrombie, Hill, and Turner (1984),

> Socialization may be conceived as the internalization of social norms: Social rules
>
> become internal to the individual, in the sense that they are self-imposed rather
>
> than imposed by means of external regulation and are thus part of the individuals'
>
> own personality. (p. 394)

Culturally, bereavement is characterized by pervasive and intense negative emotions. It is

perceived that one may experience sadness, loneliness, anguish, disbelief, hopelessness,

helplessness, guilt, anxiety, fear, and anger (Dutton & Zisook, 2005). These emotions

provide the fundamentals of knowing. These cultural expectations translate to distress

experiences by bereaved persons.

On a large-scale our social influences like friends, media, and our life experiences

support our internal guide and process our experiences. George Mead, an American

sociologist described, the self emerges through the process of social interaction with

others (Abercrombie et al., 1984). Social standards of behavior serve as conditioned

responses to include gesture and role-taking, which is the basis of social life

(Abercrombie et al.). Responses are generated from multiple ways of learning and

processed between individuals via communication.

According to one of the founders of family systems theory, Gregory Bateson

(1972) posits, "The focus of discussion was upon form rather than content, upon context

rather than upon what occurs 'in' the given context, upon relationship rather than upon

the related persons or phenomena" (p. 154). Communication therefore becomes a vehicle

that transports the lived experiences of a person or group of people. Gergen (2009) outlines, ". . . what we take to be the world importantly depends on how we approach it, and how we approach it depends on the social relationships of which we are a part" (p. 2). Another aspect of bereavement is that even in the face of grief individuals are able to draw strength and vitality from struggling with the trauma of death (Dutton & Zisook, 2005). Anderson and Goolishian (1988) posits, "Through dialogue, human systems mutually evolve their own language and confirm its meaning" (p. 2). It is a process whereby information is generated, synthesized, and regenerated to create shared meaning between parties involved.

Information shared over time and passed down from generation to generation becomes an epistemological truth. Bateson (1972) noted,

> In other words, the frequency of use of a given idea becomes a determinant of its
> survival in that ecology of ideas which we call Mind; and beyond that the survival
> of a frequently used idea is further promoted by the fact that habit formation tends
> to remove the idea from the field of critical inspection. (p. 509)

This relates therapeutically to working with persons experiencing grief as information repeated over time can generate new meaning for all those involved in the process. Neimeyer (2005-2006) reviewed grief therapy through a review of published investigations between 1975 and 1998 a total of 28 papers. The criteria was that the research was focused on bereaved persons mourning the death of a loved one who received some form of psychosocial intervention and who were randomly assigned to treatment or control condition. There was a combination of 1600 participants.

For grief therapists, these findings suggest that the meaning making processes that

are most relevant to facilitate tend to shift over time, from an early emphasis on

finding an answer to the question of 'why' the death occurred, to a later focus on

the positive (albeit unsought) benefits of the loss for the survivors.

(Neimeyer, 2010, p. 551).

The way we live our lives are through interpretative constructs of meaning. According to

Goolishian and Anderson (1987), "These attributions are, in the final analysis, no more

than linguistic inventories that name the things we take to be real and identify the objects

that can populate our realities" (p. 532). The intensity of the grief experienced can be

transformed through dialogue altering its severity.

Dutton and Zisook (2005) examined bereavement between widows and widowers

to see if there were universal accompaniments of grief. Their findings suggested, "As

painful and devastating as it can be, bereavement can also be associated with improved

coping, personal growth, and a new appreciation for life" (p. 899). This study showed a

gap in sources of their resiliency (Dutton & Zisook, 2005). Identifying coping strategies

and growth is useful as it uncovers strength based processes the individual developed

from their encounter with death, trauma, and/or loss.

Research conducted by Whitebird et al. (2013) surveyed 547 Hospice workers to

observe the effects of stress and mental health of Hospice workers in terms of burnout

and compassion fatigue as well as coping mechanisms. Their research found social

support to be a vital factor in keeping stress to a manageable level among Hospice

workers (Whitebird et al., 2013). According to a study of family therapists working with

death and dying Becvar (2003) concluded an emphasis needed on self-care of the

therapist. Becvar highlighted a gap in training and research on the topic of enhancing a therapist's well-being in Hospice settings. Becvar's research highlighted a gap in training which would allow Hospice workers to process and make sense of death narratives leading to the overall health and well-being of Hospice workers.

Anticipatory Grief

Anticipatory grief is a preoccupation with the loss of life prior to death. Kübler-Ross and Kessler (2005) explained, "We often think of it as part of the process our loved ones go through as they face their own death themselves. Yet, for those who will survive the loss of the loved one, it is the beginning of the grieving process" (p. 4). Patients experience anticipatory grief as they begin to process their terminal illness and start to mourn their death. In these cases it becomes complicated as the patient may or may not choose to share this feeling with family members. Concurrently, the family may find difficulty expressing a sort of division in their mind as they conceptualize thoughts of both holding on and letting go.

Anticipatory grief may occur months or years before the loss, and it is separate from the grief a person will feel after their loved one dies. It is a precursor, a double grief that will ultimately bring healing (Kübler-Ross & Kessler, 2005). Several factors such as a person's culture, perceptions of loss and experiences with death contribute to a variety of responses attributed loss. Grief is as individual as our lives; hence, there is no formula to work with people experiencing anticipatory or complicated grief (Kübler-Ross and Kessler). Kübler-Ross and Kessler (2005) outlined, "There are five stages of grief (denial, anger, bargaining, depression and acceptance) as a framework that makes up our learning to live with the loss of a loved one" (p. 7). Hospice Bereavement Coordinators

work with patients and families to cope and develop a frame to identify feelings

prompted by the death of oneself or a loved one.

Complicated Grief

The Center for Complicated Grief (2013) defines complicated grief as ". . . an

intense and long-lasting form of grief that takes over a person's life . . . a form of grief

that takes hold of a person's mind and won't let go"

(http://www.complicatedgrief.org/bereavement). In contrast to anticipatory grief,

complicated grief is categorized as chronic grief typically immobilizing a person from

conducting daily routines with depressive characteristics. Research conducted by Simon

(2013) identified the symptomology of complicated grief to include intrusive thoughts

about the circumstances of the death, excessive avoidance of reminders of the loss, and

an inability to regulate emotions surrounding the loss. Complicated grief stems from an

inability to make meaning of life without the person to which the bereaved created their

self-narrative (Neimeyer, 2005-2006). Feelings of numbness and trouble accepting the

loss can be seen as expressions of the inability to assimilate the death into one's previous

constructions of reality (Neimeyer, 2005-2006). A person may describe feeling that life is

empty or meaningless without the deceased and that it is impossible to move on toward a

purposeful future dialogue as it would act as assault of the survivor's sense of

significance and continuity (Neimeyer). The meaning the bereaved attributes to their life

without the deceased may predict the likelihood of whether they will experience

complicated grief.

The intervention is then to recognize images of sadness, despair, and loneliness.

Neimeyer, Baldwin, and Gillies (2006) reviewed attachment theory as a role of active

coping processes and meaning reconstruction in adaptation to loss. The researchers sought to evaluate the relationship between the bereaved adults' experience of a continuing bond with the deceased and their ability to attribute meaning or significance of the loss. The researchers also noted the bereaved person's report of complicated grief symptomatology (Neimeyer et al., 2006). The study concluded that continuing bonds with the deceased person served as a tool whereby interaction with meaning making resulted in fewer symptoms of complicated grief. Neimeyer et al. (2006) suggested, ". . . there appears to be ample conceptual, empirical, and clinical warrant for further research on the reorganization of the continuing bond, and the larger processes of meaning reconstruction of which this is a part" (p. 735). Acknowledgment of bereavement fosters trust during a difficult time in a person's life. Bereavement narratives allow a person to make sense of their loss, manage their feelings in an adaptive way, maintain emotional stability, encourage new friendships, and facilitate resilience (Dutton & Zisook, 2005).

Interpretations of death and dying are socially constructed. Lived experiences allow individuals to synthesize information through a process that generates meaning making. This is conducted through internal and external dialogues. From a social constructionist viewpoint reality is constructed through human action and does not exist independently of it. The world as a meaningful reality is constructed through human interpretative activity (Fulton, Madden, & Minichiello, 1996). Hoffman (1990) highlighted, "In therapy, we listen to a story and then we collaborate with the persons we are seeing to invent other stories or other meanings for the stories that are told" (p. 11).

Through this frame the concepts of grief, death, and loss are constructed within and between individuals and their experiences.

Traumatic Loss

The ambivalence of traumatic loss in hospice settings derives from a paradox of ambiguity and conclusiveness. Family and friends of a terminal patient fluctuate between an inevitable death and elusiveness surrounding the patient's expiration. This ambiguity creates stressors as the ". . . uncertainty simply wears people down. Individuals feel helpless, hopeless, and depressed" (Boss, 2006, p. 38). Lifestyles and events are typically placed on hold as attention to the patient's untimely death permeates. While the moments leading up to the patient's death narrows the familial anticipation intensifies. According to Boss (2006),

> In this kind of context—incomprehensible, illogical, confusing, senseless, unjust, an outside of one's control— rational thinking about how to cope is blocked. Through no fault of their own, people experience trauma and stress because the ordinary facts about the absence or presence of loved ones are shrouded in mystery. (p. 40)

Traumatic loss can be described as the last moments of a loved one's life as it elicits devastation and hopelessness for family members and friends. The finality of the last breath, the observation of the statuesque body, the immediacy of the transition from life to death creates traumatic loss.

Secondary Traumatic Stress

HBCs offer psychosocial support to bereaved family members experiencing traumatic loss. According to Rolland (1994) "Working with illness and loss heightens awareness of our own mortality. A "we—they attitude toward the families we encounter is impossible. We are helping families with issues that are inevitable in our own lives and families" (p. 270). Listening to the vivid descriptions surrounding the narratives of traumatic loss can create issues for clinicians as they absorb the impact of their work. At times the disoriented griever is an employee, struggling to balance the demands of grief with the ongoing responsibilities of the workplace (Jenko, Seymour, and Stone, 2011). According to Pearlman and Saakvitne (1995) "The term secondary traumatic stress disorders (STSD) . . . describe the responses individuals have to hearing about others' traumatic experiences" (p. 151). In working with families who are experiencing traumatic loss, a HBC must be cognizant of the profound impact it can have on their psyche. Pearlman & Saakvitne (1995) noted, "While it is work we enter into by choice, and continue because of a commitment to our clients and because of the tremendous rewards we can experience, we must recognize that it affects us personally" (p. 151). Secondary traumatic stress symptoms are typically event related which are manifested by sleep disturbances and avoidance of reminders of the event (Smart et al., 2014). Despite an employee's efforts to cope and compartmentalize, grief invades in countless ways which result in lessened productivity and low morale (Jenko et al., 2011). Secondary traumatic stress may increase the emotional intensity of HBCs.

CHAPTER III: METHODOLOGY

The researcher will describe the qualitative design and phenomenological research methods implemented to capture the lived experiences of HBCs at a faith-based Hospice organization in South Florida. This will outline the structure of the research. A description of the participant selection, inclusions criteria, and ethical considerations will frame the parameters of the research. Additionally, variables and data analysis procedures are documented.

Qualitative Paradigm

A qualitative research design was appropriate to capture the essence of meaning of death, trauma, and loss derived from HBCs working with patients and families exhibiting anticipatory or complicated grief. Creswell (2013) described, "Qualitative research begins with assumptions and the use of interpretive/theoretical frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem" (p. 44).

Qualitative research allowed a greater knowledge through dialectic methods of gathering information from participants. Exploring the meaning which surrounded loss and death narratives through first-hand accounts from HBCs allowed the essence of their experience to unravel. The process of qualitative research flowed from philosophical assumptions, to a study of the problem, to a collection of data and analysis to establish patterns or themes (Creswell, 2013). Qualitative research uncovered the meanings attributed to multiple forms of loss to capture the essence of the phenomena.

The challenges HBCs faced, feelings associated with their job, satisfaction as well as disappointments, and other experiences were revealed through qualitative designed

interviews. Through semi-structured questions, participants explored specific details surrounding their experiences of working with and through loss.

Phenomenology Research Method

Edmund Husserl (1999) was a pioneer of phenomenology. Husserl described phenomenology as ". . . a new kind of descriptive method which made a breakthrough in philosophy at the turn of the century. . . a science which is intended to supply the basic instrument (Organon) for a rigorously scientific philosophy. . . " (p. 323). Phenomenology is the notion of incorporating the interpretative nature of words to uncover the true essence of an experience from a first-person account of the nature of the phenomena. Husserl explained:

> Through reflection, instead of grasping simply the matter straight—out—we grasp the corresponding subjective experiences in which we become "conscious" of them, in which (in the broadest sense) they "appear." For this reason, they are called "phenomena", and their most general essential character is to exist as the "consciousness-of" or "appearance-of" the specific things, through (judged states of affairs, grounds, conclusions), plans, decisions, hopes, and so forth. (p. 323)

Through socialization individuals come to view the world through a lens they interpret as "fact." Minimal consideration is given to the internal meaning derived from a thing or object from a personal individual account. This premise allowed the researcher to understand the perceived norms of preparing for the death of a patient and working with

cases of anticipatory or complicated grief. Husserl (1999) described,

> As soon as the theoretical interest abandons this natural attitude and in a general
>
> turning around of our regard directs itself to the life of consciousness—in which
>
> the "world" is for us precisely that, the world which is present to us—we find
>
> ourselves in a new cognitive attitude (or situation). (p. 323)

This concept validated the meaning of an experience by an individual. The researcher then accounted for the subjectivity of the individual and his/her consciousness of the experience.

This research sought to go beyond the general questions of knowing the job description for HBCs, a phenomenological approach allowed participants to explicitly outline internal and external factors encountered from loss. Their perceived notion of preparation for death and guidance on how best to prepare for the duties required by their job, manifested. Meaning was then created when the experience or object a person was consciously aware of, was communicated without the biases of the researcher. For this to occur, the researcher incorporated transcendental phenomenology.

Transcendental Phenomenology

Transcendental phenomenology is concerned with the description of phenomena through the lens of the participants. It is the ability to transport the psychological, sociological, and biological meaning surrounding a phenomena, while removing the biases of the observer or researcher in order to capture the total meaning from the perspective of different people who experienced the phenomena.

An American Psychologist, Clark Moustakas (1994) developed a qualitative research approach based on Husserl's (1999) phenomenological philosophy utilized in

this research. For Moustakas, a phenomenon of any kind is a place to start an investigation about the perception of a thing both in appearance and emotions exhibited from the encounter. Moustakas (1994) noted, "The challenge facing the human science researcher is to describe things in themselves, to permit what is before one to enter consciousness and be understood in its meanings and essences in the light of intuition and self-reflection" (p. 27). Moustakas emphasized the nature of a neomatic or textural relationship and a noetic or structural dimension of phenomena. In order to capture the true meaning of the lived experiences the researcher employed specific applications of phenomenological reduction.

Phenomenological Procedures

Methods and procedures allowed the researcher to follow a step by step process for preparation and collection of data whereby conducting interviews, organizing documents and analyzing data provided a coherent portrayal of the experience being investigated (Moustakas, 1994). Utilizing Moustakas' theoretical underpinnings of phenomenology based on Husserl, the researcher employed specific applications of phenomenological methods. Phenomenological reduction incorporates: epoché or bracketing, transcendental phenomenological reduction, imaginative variation, and synthesis.

Epoché or Bracketing

Epoché is a Greek word meaning to refrain from judgment or abstain from every day, ordinary ways of perceiving things (Moustakas, 1994, p. 33). According to

Moustakas (1994), ". . . epoché requires a new way of looking at things, a way that requires that we learn to see what stands before our eyes, what we can distinguish and describe" (p. 33). Bracketing was important for the researcher to express their personal biases about the research question. This allowed the researcher to set aside philosophical assumptions about the phenomena. Moustakas (1994) described, ". . . it moves beyond the everyday to the pure ego in which everything is perceived freshly, as if for the first time. . ." (p. 34). A list of the researcher's personal biases and assumptions follow:

1. Hospice Bereavement Coordinators have unidentified processes for working with patients and families experiencing grief.

2. Hospice Bereavement Coordinators create a wall when experiencing the loss of a patient in order to appear psychologically competent to work with anticipatory or complicated grief.

3. Hospice Bereavement Coordinators derive meaning from the losses they encounter although rarely discussed.

4. Hospice Bereavement Coordinators seldom provide psychosocial support to each other which could serve as a resource for identifying self-care.

5. Hospice Bereavement Coordinators experience secondary trauma when graphic accounts leading up to a person's death is retold during therapy.

Outlining assumptions allowed the researcher fulfill the required step of epoché or bracketing. The researcher utilized journaling to process struggles, if any, encountered to conduct this phenomenological research.

Transcendental-Phenomenological Reduction

Transcendental-phenomenological reduction was built on the psychological reduction of epoché. According to Moustakas (1994),

> In the Transcendental-Phenomenological Reduction, each experience is
> considered in its singularity, in and for itself. The phenomenon is perceived and
> described in its totality, in a fresh and open way. A complete description is given
> of its essential constituents, variations of perceptions, thoughts, feelings, sounds,
> colors, and shapes. (p. 34)

Data collection for transcendental-phenomenology uncovers themes, meanings, and essences of human experience through the analyzed data (Moustakas, 1994).

The researcher prepared a textural and structural description of the participants experience in order capture the overall essence of their lived experience. A neomatic or textural description acknowledged that what a person viewed to be reality was in fact reality (Moustakas, 1994). A noetic or structural description recognized how the participant interpreted and conceptualized their experience (Moustakas). This allowed the researcher to describe internal and external relationships within the context of the phenomenon. As Moustakas (1994) noted , "Ultimately, through the Transcendental-Phenomenological Reduction we derive a textural description of the meanings and essences of the phenomenon, the constituents that comprise the experience in consciousness, from the vantage point of an open self" (p. 34).

Imaginative Variation and Synthesis

Imaginative variation is aimed at grasping the structural essences of the experience (Moustakas, 1994). This process allowed the researcher to gain a structural

description of the essences of the experience and generate multiple frames to interpret the phenomenon. According to Moustakas (1994), ". . . the structural essences of the Imaginative Variation are then integrated with the textural essences of the Transcendental-Phenomenological Reduction in order to arrive at a textural-structural synthesis of meanings an essences of the phenomenon or experience being investigated" (p. 36). During this process themes were generated. Once the themes are formulated the researcher synthesized meaning in order to capture the experience of the phenomenon.

Data Collection

Participant Selection

The researcher utilized purposeful sampling to select six participants. To solicit participation in the research study, the researcher sent the IRB approved letter of intent to upper administration at Catholic Hospice via e-mail (See Appendix B). The researcher then gained approval from upper administration to reach out to the HBCs and Hospice Chaplains. Once approval was granted the researcher sent an e-mail to HBCs and Hospice chaplains to recruit their participation via the approved IRB letter. The participants were selected based on their experience with the phenomenon.

Participants

Three responded via e-mail and contact was made with five respondents via telephone call. Due to scheduling conflicts, of the eight respondents the researcher yielded six participants. All participants worked in the South Florida area. Three participants were HBCs and three participants were Hospice Chaplains. All participants worked at Catholic Hospice for more than one year. All participants noted they had not

thought of working in a hospice setting prior to their employment with Catholic Hospice therefore, this was their first employment experience working in a hospice setting.

Inclusion Criteria

The researcher then recruited participants via e-mail (See Appendix C). The email discussed the purpose of the study. The e-mail explained the research question, the identified need for conducting the research, and the role of participant involvement. Attached to the e-mail was an informed consent form which was reviewed and signed prior to the start of the interview (See Appendix D). Informed consent allowed the participant to review all aspects of the research study and potential risk factors.

The inclusion criterion for this research study included:

1. Current employment at the identified faith-based hospice located in South Florida, in a role providing therapeutic support to patient-family units coping with anticipatory or complicated grief;

2. Six months or more of experience working with patients and families who have experienced anticipatory or complicated grief;

3. Experience with losing multiple patients in a Hospice setting; and an

4. Ability to meet for a one and a half hour interview.

Interviewing

Once contact was made, the researcher worked with the participants to schedule a day and time to meet. Upon arrival, each participant was given a printed copy of the consent form and tighter with the researcher each section was reviewed. The participants signed the consent form and the option of a signed copy was given to each participant, three of the six participants requested a copy of the signed consent form. The researcher

informed each participant that the interview would begin and the digital-audio recorder's

play button would be pressed.

Participants were digitally audio-recorded during an interview which lasted

between twenty and forty-five minutes conducted in a secure location within the faith-

based Hospice. The researcher conducted all interviews and identified participants by

letters (i.e., A, B, C, etc.). Semi-structured open-ended questions were utilized to capture

the experiences surrounding the phenomena. These questions served as a guide to

facilitate the interview process. Open-ended questions are listed in Appendix E.

All six participant's interviews were digitally-audio recorded. The researcher

followed the epoch principle of phenomenology by utilizing a journal. After each

interview the researcher processed the interview in a journal to interpret information

being discussed.

Setting

The interviews were conducted by the researcher at several Catholic Hospice

locations in South Florida. Interviews were conducted in early 2015. The semi-structured

interview questions prompted participants to detail their experiences working in a high

stress high loss environment. The participants choose a location within Catholic Hospice

that was closer in distance to the territory they covered and a time most conducive to their

work schedule was confirmed. All interviews were conducted in a secure location.

<div align="center">

Data Analysis

</div>

A computer with password protection was used and stored in a secure locked

location. The data analysis process began once the researcher began to transcribe the

interviews conducted. The researcher played interviews on a slow speed to transcribe

interviews with the use of headsets to secure confidentiality. The recordings were typed

into a Microsoft Word Document. Through the use of Moustakas (1994) organization of

data, "The procedures include horizonalizing the data and regarding every horizon or

statement relevant to the topic and question as having equal value" (p. 118). The

researcher read through each participant's interview transcript and highlighted significant

statements. This provided an understanding of how the participants described their

experience of the phenomena. This allowed the researcher to capture significant

statements that related specifically to the research question.

Next, the researcher developed meaning units from the horizonalized statements.

These horizonalized statements were grouped into clusters to "remove overlapping and

repetitive statements" (Moustakas, 1994, p. 118) that formed themes. Clustered themes

and meanings served as textural descriptions of the experience. Textural descriptions are

the words used to identify the qualities of the experience. These descriptive words were

examined within the context it was being experienced to capture the essence of the

experience. Then, structural descriptions were gathered. Structural descriptions are the

researcher's reflection and interpretation of the participant's story. An integration of

textures and structures were combined to create meanings and essences of the

phenomenon were constructed (Moustakas, 1994). The researcher wrote personal

accounts of the experience surrounding the research in Chapter IV.

Ethical Considerations and the Institutional Review Board

All participants of the study were treated in accordance with ethical guidelines of

the American Association of Marriage and Family Therapy (AAMFT) and the Nova

Southeastern University Institutional Review Board (IRB). Human science researchers

are guided by ethical principles on research conducted with human participants (Moustakas, 1994). Agreements between the researcher and the research participants were disclosed to include the ". . . nature, purpose, and requirements of the research project" (Moustakas, pp. 109-110). The researcher ensured the confidentiality and consensual agreement between participants by securing all information in a locked cabinet with access only given to the researcher. Participants had the freedom to withdraw from the study at any time without explanation. Participant information included:

1. The nature of the study;

2. Rationale for participation in the study;

3. Participant roles toward findings;

4. Digital audio-recordings;

5. Description of any potential danger to participants;

6. Detailed benefits to participants, if any;

7. Financial obligation or reward for participation in the study;

8. Confidentiality of information;

9. Participant ability to leave the study at any time;

10. Confidentiality of answers from participants questions pre, during, and post research study; and

11. Voluntary nature of participant consent in the study.

All digital audio-recordings and documents related to the research study will be destroyed three years after the study is completed.

The dissertation chair, dissertation committee, the IRB representative from Nova Southeastern University, and the researcher were the only people able to access the confidential files. Participants are anonymous and referred to by a letter (i.e., A, B, C, etc.). Due to the nature of this research study, "The importance of self-reports in data collection was emphasized so that the research participant felt his or her contributions were valued as new knowledge on the topic and as an illumination of meanings inherent in the question" (Moustakas, 1994, p. 110). The researcher biases were written and processed in the journal throughout the study (See Appendix F). This method of journaling allowed the researcher to "bracket" their experience to ensure the authenticity of meaning gathered from research participants.

Validation and Verification of the Data

The validity of phenomenological research is important. The researcher via e-mail contacted participants and asked if they would participate in a voluntary meeting to review an analysis of the data collected from their interview. The researcher reviewed a copy of the synthesis of textural-structural descriptions gathered from four of the six participants which clarified and validated the meaning ascribed through the interview; this is referred to as member checking. Member checking served to verify a unified meaning generated from the interview and allowed research participants to add or correct the researcher's synthesis from the interview (Creswell, 2013).

The researcher also presented findings to the dissertation chair and the committee members to support the integrity of the research. The dissertation chair and the committee members ". . . keep the researcher honest; ask hard questions about methods, meanings, and interpretations; and provide the researcher with the opportunity for catharsis by

sympathetically listening to the researcher's findings" (Creswell, 2013, p. 251). Through this open dialogue between the researcher, the dissertation chair, and the committee synthesis of the qualities and meanings of the phenomena were verified.

Verification of the data was conducted by listening to the digital audio-recordings multiple times. This ensured that the researcher was capturing how the participants are describing their experience. Verification of the collected data and data analysis added to the trustworthiness and authenticity of the research study (Creswell, 2013).

CHAPTER IV: FINDINGS OF THE RESEARCH

The purpose of the research study was to explicate the meaning HBCs and Hospice Chaplains ascribed to their lived experience of death, trauma, and loss working in hospice settings with patient-family units exhibiting anticipatory and/or complicated grief. Findings of this inquiry will include methods of reducing and interpreting lived experiences as well as a description of themes.

Reducing and Interpreting Lived Experiences

Moustakas (1994) noted phenomenological data analysis as a process of reduction and interpretation of lived experiences. Utilizing this method, the researcher created a textural description of each participant's lived experience. Secondly, a structural description of the phenomenon provided reflection and interpretation (Moustakas, 1994). Lastly, the significance of the researcher's journal was discussed.

Textural Description

The textural description intended to gather a description of the lived experience of the participants to capture what the participants actually experienced. To facilitate the textural description within this research study each participant's experience was organized by the responses given to each question. The researcher chose to use Excel as a data analysis tool because it allowed a review of transcriptions and view of original texts to be sorted. Phenomenology allowed the researcher to constantly reflect on perceptions of statements made by participants while epoch allowed the researcher to remain nonjudgmental toward the participant's narrative.   These textural descriptions were then placed into a Microsoft Excel document, shown in the example below, Table 4.1.

Table 4.1

Textural Descriptions

Question	Participant A	Participant B	Participant C	Participant D	Participant E	Participant F
How would you describe loss in the context of your job?	Losing someone in the physical sense. . . losing so much in one person so my idea of loss is always in the physical sense but I always feel like their presence is there in some way whether it's through memory, or things of that nature.	Loss is a deep irreparable hole or wound that is very difficult to heal if at all in my own case I still very sharply feel the loss of my father. . . loss is minimal but most of the time it's a relationship that has been thrust to a place that neither participants really want to be in but now they are there, one is no longer participating and one has to participate without the other one and uhm, it's my job to try to help the participant do what they did previously but without their doubles partners so to speak.	Again, some say this may sound strange, but . . . there is a circle that death does not exist, death is life, but death brings new life and everlasting life, so that's how I view death right now.	Loss is a difficult time for people ah like suffering it's a distressing part in their life it's difficult for most people because at that time not everybody is ready to say goodbye to their loved ones.	I think that the families have a very difficult time accepting loss and I think it's because the relationship has not been that great with the person that has passed away, but I think that its' because physically they are not going to be there anymore, it's not the problem of that person dying it's the problem that the physical aspects, the person being there on a daily basis whether they are taking care of them or not I think that's when you know the families seem to have more difficult times accepting the family member that's dying or gone.	The absence of something that you care for.

The researcher re-read transcriptions and highlighted phrases that were pertinent to the

research question. Through this phenomenological process of horizonalizing the data the

researcher was able to capture meaning units or horizons as statements relevant to the

topic were identified (Moustakas, 1994), as shown below in Table 4.2.

Table 4.2

Horizonalized Statements

Participant A	Participant B	Participant C	Participant D	Participant E	Participant F
Losing someone in the physical sense. . . losing so much in one person so my idea of loss is always in the physical sense but I always feel like their presence is there in some way whether it's through memory, or things of that nature.	Loss is a deep irreparable hole or wound that is very difficult to heal if at all.	My perception is that those are losses, they are physical.	Loss is ah a difficult time for people like suffering it's a distressing part in their life. . . it's difficult for most people because at that time not everybody is ready to say goodbye to their loved ones.	I think that the families have a very difficult time accepting loss and I think it's because the relationship has not been that great with the person that has passed away, but I think that it's because physically they are not going to be there anymore, it's not the problem of that person dying it's the problem that the physical aspects, the person being there on a daily basis.	The absence of something that you care for.
	Death and loss are not interchangeable but they go hand in hand, loss is what happens after the patient's death and it's a palpable part of what the family goes through.		A loss, if you lose something in your life you feel empty if you lose a I don't know your hope.	Loss everybody goes through it.	

The researcher reflected on whether the statements captured the essence of the

participant's experience then, verbatim statements were clustered together.

Structural Description

The structural description allowed the researcher to validate the interpretation

through structural statements taken from textural descriptions (Moustakas, 1994).

Interviews were listened to again while reading the transcriptions in order to modified

information. Connections between ideas and overlapping ideas were tracked in a

notebook and then transferred into an Excel document (Moustakas, 1994). The Excel

document provided a visual of the clustered categories as seen below in Table 4.3.

Table 4.3

Clustered Categories

Category	Participant A	Participant B	Participant C	Participant D	Participant E	Participant F
Loss	Loss is physical and learning to live without the patient	Loss and learning to live without the patient	Loss is a gain into eternal life	Loss is physical	Loss is the absence of	Loss is the absence of

The analysis represented reflections of the researcher's interpretation of what the

participants meant by their descriptions of working with death, trauma, and loss. Through

imaginative variation the researcher began to read each of the statements and wrote down

interpretations of participant responses to generate themes, shown in Table 4.4.

Table 4.4

Generating Themes

Theme of Death					
Participant A	**Participant B**	**Participant C**	**Participant D**	**Participant E**	**Participant F**
a happening	initiating work	transitional renewal of life, a beginning	faith in another world	a process not a finality	unavoidable and fragile
finality	a reality	the encountering with God	continuing life	a physical uncontrollable process	a normal part of life
a part of life, a finality, and is physical	uncontrollable	physical	going to a better place	has no immunity	strengthens spirituality
going away from to live spiritually	causing reactions	an everlasting continuum of creating			
↓	↓	↓	↓	↓	↓
being transformed from physical to live in an afterlife	an inevitable force that creates change	being transformed to a renewed state to meet the creator	being transformed to an afterlife	being inevitably forced into a continuum	being transitioned into a natural renewal of spirituality
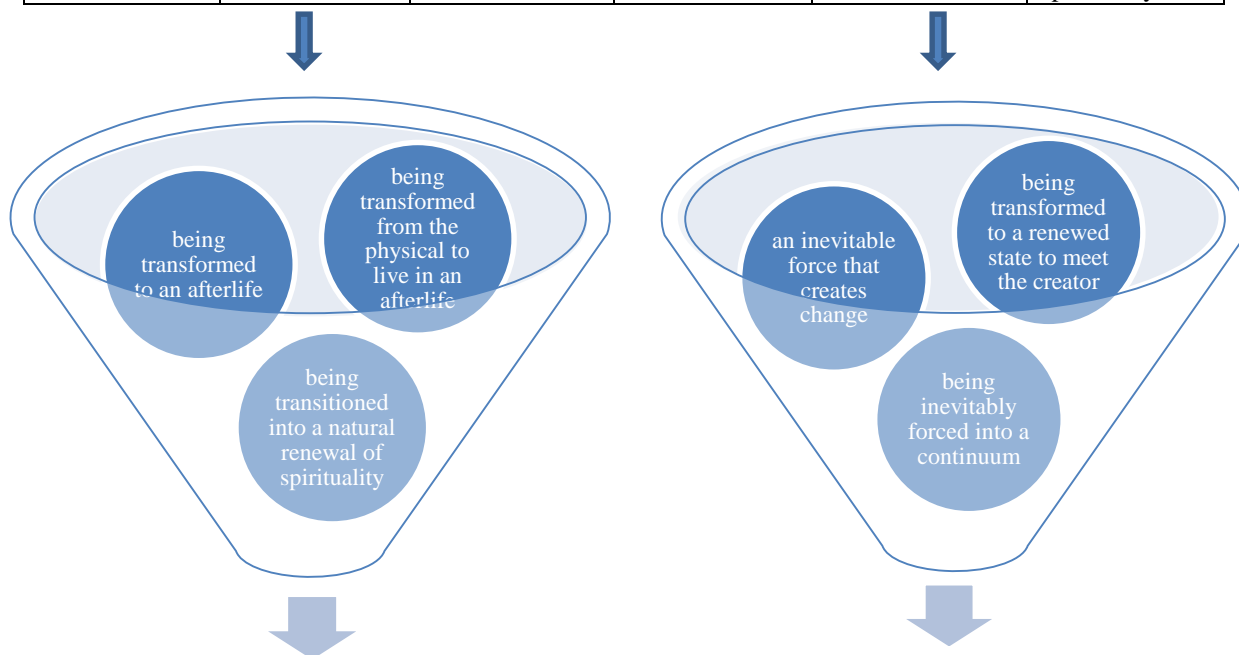
A transition to immortality

An intense progression

The researcher typed out themes and reviewed themes to make adjustments. All themes captured from the analysis were written in a notebook and grouped into larger themes. The larger themes were typed into an Excel document next to each participant's statement and grouped together. This process occurred as themes were compared to statements within the transcripts. The researcher also reviewed the literature for this dissertation and considered additional ideas that were relatable to the interview transcriptions to capture deeper meanings from the verbatim statements of participants. Through imaginative variation a reflection of the researcher's interpretation of possible meanings of the phenomenon was generated to represent the experiences of the participants. An e-mail was sent to participants requesting their participation in a voluntary follow-up meeting to discuss the researcher's interpretation of their responses.

Four out of the six participants met with the researcher to review comments made about their responses to ensure there were no misinterpretation of their views. One of the participants added to the comments made by the researcher "We can consider our life based on past experiences, present experiences, and know the future is in God's hands, death is the only reality we have in our life." This process of member checking allowed participants to view their transcribed interview and summaries of their interview. The analysis was completed by creating a composite description of clustered themes to form a list of themes and categories, shown in Table 4.5.

Table 4.5

List of Themes and Categories

THEMES	PARTICIPANTS:	A	B	C	D	E	F
1. Death is an earthy transition to immortality		X		X	X		X
2. Death is an intense progression		X	X	X	X		
3. Trauma is an interpretive response to a bad experience		X	X	X		X	
4. Trauma highlights quality of life		X	X			X	
5. Loss is an adaptation to change		X	X		X	X	
6. Loss highlights self-awareness about mortality		X	X	X	X	X	X
7. Cases impact views of death, trauma, and loss		X	X	X	X	X	X
8. Influences of spirituality		X	X	X	X	X	X
9. Stressful aspects of working in hospice settings		X	X	X	X	X	X
10. Methods of coping		X	X	X	X	X	X

Description of Themes

Ten central themes emerged from this study as seen in Table 4.5: Death is an earthy transition to immortality; Death is an intense progression; Trauma is an interpretive response to a bad experience; Trauma highlights quality of life; Loss is an adaptation to change; Loss highlights self-awareness about mortality; Cases impact views of death, trauma, and loss; Influences of spirituality; Stressful aspects of working in hospice settings; and Methods of coping. To capture the essence of meaning derived from the interviews it is important to hear the words each participant used to describe their experiences.

Death is an Earthly Transition to Immortality

Four out of the 6 participants viewed death as a transition from a physical life to a spiritual life.

Participant A. The participant's statement described ". . . the meaning for death and dying I see that as it being their time to go maybe God doesn't want them on this earth and he has another purpose for them in heaven." The assumption that "it is their time to go" eluded to the departure from one place to another. The participant further stated, ". . . maybe God doesn't want there on this earth and he has another purpose for them in heaven." Within this remark was the notion of the body being left behind for the pursuit another life form.

Participant C. Death was viewed as a mere vanishing of the physical stating "physical is death", to a life conquering the physical body "life goes beyond death." To go "beyond" the physicality suggested there is something more to become.

Participant D. The participant referred to death in this way,

". . . when I started working here I learned how to see that death like is all things, I don't have fear to see people dying and I think that that in time with my faith we live in this world but we are going to a better place."

Death became an outlet to enter into another dimension. Through faith this participant showed the shift of thought from a "fear to see people dying" to the certainty that when we die "we are going to a better place." This alleged "place" assumed the person journeying to another dimension in a different form.

Participant F. This participant described, "Death is normal that its part of life and that we have to be prepared." To be "normal" implies a natural level of expectancy. An

expectancy that all living things endure this "part of life." The participant spoke

of a preparation needed to get there. The preparation for something assumed a

need to get ready for something to come. The natural process a person goes

through to die served as the preparation needed for them to move on from this life

(place) to another.

Death is an Intense Progression

Four out of the 6 participants viewed death as an inevitable renewal of the self.

Participant A. Death was described as a part of life.

> Death, I think that it's something that I realize is a part of life. You can't
>
> control it and so in me being spiritual, I don't see death as final. I see the
>
> physical, they're not there physically but they are there spiritually and
>
> their legacy lives on through their memories.

The description of death was something that could not be controlled highlighting

the inevitability of death.

Participant B. Death was viewed as an uncontrollable reality ". . . I can't stop death or

slow it down even" and "it's (death) is more real." The inability to control

something was to succumb to its undeniable force. There was implied acceptance

as it becomes "more real." If something is real, valid, it is a fact. The reality of

death then brings the truth living beings are faced with.

Participant C. Illustrated death as a transitional renewal of life from the physical to the

ethereal. "There is a circle that death does not exist, death is life, but death brings

new life and everlasting life, so that's how I view death right now." Death

initiated the beginning of a continuum. The participant referred to a "circle", a

shape with no beginning or end. Within the statement the participant also

mentioned an "everlasting life." Everlasting meant no end. Participant C further

stated,

> Oh definitely, in life we are in constant movement life. Death is not the
>
> end it doesn't end it's the beginning of a new life you know, everything in
>
> the universe is in continuous creating because God cannot stop creating
>
> because the moment God stops creating then God is dead, and God is
>
> eternal he doesn't have a beginning or end. God is, so he is a loving
>
> creator in spite of new theories or philosophical ideas about you know
>
> God today.

Life then goes around and around "God cannot stop creating." The circle, a shape

without angles to stop movement. Death became a movement from one place to

another.

Participant D. Illustrated the way patient-family units adjust to make sense of their lives

following the death of a loved one.

> Sometimes if you are very involved it depends because sometimes we are
>
> working and we are trained to support everybody but at the same for
>
> everybody, but there are special people that you get more in touch with
>
> them and it's kind of affect you as a human being because you are caring
>
> and warm with the patient and the family and they become special persons
>
> to you and at the end you are maybe suffering and crying with the family
>
> but it's a wonderful experience because at the same time that you are
>
> suffering with them and praying with them you're supporting them and

you are giving them hope and you are you know giving them the signs of how they can get again life.

When a family faces the death of a loved one they adjust to a life without a person they cared for.

Trauma is an Interpretive Response to a Bad Experience

Two out of the 6 participants discussed traumatic circumstances that occur during end-of-life.

Participant A. Trauma was a response to witnessing the effects an illness played during end-of-life and the family's helplessness as a bystander.

It's hard to attribute meaning to a trauma it's hard to attribute you know why does certain family members have to see their person struggling for a long time why does that person have to gasp for breath when they die or why do they have to be in pain, I don't know how to take meaning from that especially positive meaning.

The dying process was depicted as a traumatic experience as a patient would have to "gasp for breath" or "be in pain."

Participant C. Trauma was viewed as witnessing the effects of an illness without the ability to provide consolation.

Trauma is sickness, but as you view those incidents in your life irrespective of faith you might have feelings of sadness, despair, still you might question God, you know why, but the question that we should ask God is what was the purpose of that.

With a person's ailing health a family may feel "sadness" or "despair" these emotions sometimes cause a family member to "question God." Through a traumatic situation family members look to God for a deeper meaning "God what was the purpose of that."

Trauma Highlights Quality of Life

Four out of the 6 participants gave examples of traumatic situations they encountered.

Participant A. This participant detailed the process of an illness and the experiences loved ones bear witness to.

> Not having quality of life is trauma seeing your loved one slowly deteriorate for years and watching them slowing get better then not eat. That is trauma seeing your family members stop talking seeing your family members just forget who you are because they have dementia you know that is all traumatic for a family to go through when they are used to having their parents. You know having all those positive memories of them and then they are alive and here but they are not really here that's hard for anyone to go through and its traumatic for them and it can leave scars months, years after the death, as far as the dying that perspective with my job uhm, dying is something that I think people just don't (pause) people just don't think it will happen when it happens uhm, dying is something that isn't fair to a lot of families that is not right and it's like they understand that its part of life but they are never really ready for it.

Patients sometimes present with illnesses that gradually "deteriorate for years." To deteriorate implied getting worse or declining. Eventually some illnesses cause patients to "stop talking" or "just forget who you are." During this time a family may hold on to "positive memories of them" as the pain of watching them lose their sense of self becomes "hard for anyone to go through and its traumatic for them." This painful time plays an emotional toll and "it can leave scars."

Participant B. Trauma was seen as making changes to a decision that could result in a family dilemma. A shift from the desire to keep a loved one alive to a judgement call on their quality of life revealed the traumatic effects of decision making.

> Trauma (exhale) I don't deal with trauma. . . if a question arises which it could should we insert a feeding tube into my mom, should we remove a feeding tube, that becomes a question of quality of life and that is much easier to deal with, will the feeding tube improve your loved ones quality of life, will they get besides nourishment, will they get anything out of it by putting it in that they are not getting now, and conversely if they've tolerated it for this long, however long it may be, what will happen if we remove it, will they be able to uh, take nourishment without the tube, will their quality of life stay the same, get better, or get worse, I can deal with that, it's a lot easier.

As the patient's illness progresses families are faced with questions of "will the feeding tube improve your loved ones quality of life" in this case the family has to step outside of the anticipation of losing the patient to a place of whether this is a viable treatment option due to the patients current condition. Conversely, for

patients that have a feeding tube the dilemma family members faced was "if we remove it, will they be able to uh, take nourishment." To detach the feeding tube the family faced with the same option, "will their quality of life stay the same get better or worse." The complexity of this type of case created a dialogue between the family and the participant to one "I can deal with that, it's a lot easier." The ability to walk a family through a difficult decision can be both traumatic for the family and the HBC or Hospice Chaplain.

Participant C. The participant viewed trauma as,

> "Trauma for other people when I see them is the way that they cannot deal with living situations and you know their lives are you know stressful things, difficult or troubled times."

The inability to find a way to cope with the anticipated loss of a loved one leaves family members in "difficult or troubled times."

Participant E. This participant highlighted a situation where a patient did not receive any nourishment for one month.

> It was very traumatizing for me because I didn't think a body could sustain itself over a month without any nourishment and then you look at these cases where you say that's incredible how can that happen and yet you other cases where the person goes away the person passes away in a couple of days and you know so what did that person do that she was able to hold on for over a month without any nourishment and this other person that passes away in just a couple of days was taking nourishment up until the last minute.

Loss is an Adaptation to Change

As the researcher continued to review the data another theme emerged, all participants expressed loss as a time during which a loved one would no longer physically present. Five out of the 6 participants referred to loss as a time that required adjustment from the way things were to their current situation.

Participant A. Loss was viewed as missing the physical element of a person and an end to shared times together.

Loss in the context of my job, I would describe loss as you losing someone in the physical sense, uhm, the majority of my clients lose a spouse so their loss to me is compounded loss because you are not just losing one person you are losing so much of that person you are losing your spouse, your cook, your mechanic, you are just losing so much in one person so my idea of loss is always in the physical sense but I always feel like their presence is there in some way whether it's through memory, or things of that nature.

Participant B. This participant described loss as losing a loved one and no longer being able to share moments with them again.

Loss is a deep irreparable hole or wound that is very difficult to heal if at all in my own case I still very sharply feel the loss of my father . . . uhm, some people aren't hurt as deeply as others uhm, for various reasons it could be because the relationship just wasn't there in which case the loss is minimal but most of the time it's a relationship that has been thrust to a place that neither participants really want to be in but now they are there,

one is no longer participating and one has to participate without the other

one and uhm, it's my job to try to help the participant do what they did

previously but without their partners.

Participant D. This participant described the hardship of letting go of a loved one even if

you are not prepared to start to think about a life without them in it.

Loss is difficult time for people like suffering like a distressing part in

their life for human begins and it's difficult for most of the people because

at that time not everybody is ready to say good bye to their loved ones.

Participant E. This participant described the physical loss families experience when their

loved one passes away and the lack of sharing moments with them again.

Okay, well uhm, I think that the families have a very difficult time

accepting loss and I think it's because the relationship has not been that

great with the person that has passed away, but I think that it's because

physically they are not going to be there anymore, it's not the problem of

that person dying it's the problem that the physical aspects, the person

being there on a daily basis whether they are taking care of them or not I

think that's when you know the families seem to have more difficult times

accepting the family member that's dying or gone.

Participant F. This participant stated loss as an inability to be with someone you exhibit

emotions toward, "The absence of something that you care for."

Loss Heightens Self Awareness about Mortality

After further analysis, it was revealed that 6 out of the 6 participants interviewed in this research study began to question their own mortality.

Participant A. This participant provided feelings about their outlook on the dying process.

> I don't, I'm not scared of death I don't think I was ever really scared of death but I think I am now more aware of the options I would want to take or I would want my family to take when it comes to their end of life care so I think I'm just more aware and my mind is less, my mind is more to talk about it and figure out what everyone would want and I'm more so recognizing that death is something that could happen at any time as opposed to me never really think that I could lose my mom or dad, its more real to me that this could happen, what makes my family different from the other families so I'm just more in tuned with death I guess so I guess that is how its changed.

Participant B. The concept of facing their mortality was discussed.

> Yes, it's more real, uhm, when I was thirty fifty seemed very old . . . I have come to, I have come face-to-face with the reality of the, of the uhm, terminality of my life, not that I am dwelling on it or that I am thinking about it constantly but it's different now, dealing with this as it had been in the past, in the past it was something I dealt with a parent, a friend . . .this is more personal and it makes it more real than it ever had been in the past, uhm, even though I have had to deal with death in my own situation

with the death of my own father. . . death has become more real for me

now than it's ever been, I try not to let it get in my head uhm, because, that

would ah, adversely affect what I do but yeah, it's there but I try to push it

all the way to the back there.

Participant C. This participant discussed their thoughts of dying.

It makes me think about my own mortality, my own situation, my own

relationship with God, cause I'm going to be facing those problems too I

just don't know when, but that's something that I think a lot about it.

Participant D. This participant reflected on the possibility of developing a terminal illness

and their mortality.

You know but when I see death about me, sometimes I have been

reflecting and sometime ago I felt like a pain in my lung and I used to

smoke and I was asking to myself maybe this is the time because if you

have lung cancer you don't have many opportunities you know, and I said

okay if I got to go, it's not a problem, you know I lost the fear of death or

to die.

Participant E. This participant provided insight about losing loved ones and feeling like

they were in front of death's line.

I do question my mortality a lot now a lot more than I used to but I'm

guessing that's because my mom passed away and I feel I was pushed to

the forefront I'm next in line you know and it's made me feel that way and

when my dad passed away . . . it made me feel it even more because so

that's it, that's me I'm up at the front you know my dad's not there

anymore my mom's not there so it's me I'm next I'm next in line so you

know it's a little bit scary but there is no reason to feel you know afraid of

it because it's such a natural process in life . . . .

Participant F. This participant presented the negative impact learning about a terminal

illness and how coming to terms with dying could alter a person's personality.

You never know when death is going to come to you yeah that's the

reality and sometimes uhm it's not so good because it makes you think too

much about it and you can become negative that's why you have to try to

make balance from that and see that its part of life but I can't think all the

time that something bad is going to happen to me because it can happen

that you can become negative about things around you.

Cases Impact Views of Death, Trauma, and Loss

Six out of the 6 participants were asked if there were some cases that stood out

more than others, all participants identified cases. The cases participants discussed were

ones in which the dynamics of a case changed their perspective about their work and their

life. The participants discussed circumstances surrounding cases that helped them to

generate meaning about death, trauma, and loss in the context of their job.

Participant A. This participant illustrated a case where the family experienced a loss and

there were discrepancies on the death certificate. The participant noted how

outside influences can cause a family to delay the grieving process which adds

complexity to the loss of not having the person present. These outside factors

compounded the meaning of the person's death and added to the complexity of

their job.

Yes there are like the one I just mentioned because I mean, that's very hard uhm, but , another one that stands out is I had a family that had lost well it was a wife and her two children, all adults and they lost their husband and uhm, again another family who wasn't, well I guess you're really never ready but they weren't really but they didn't expect to lose him when they did lose him and there was something wrong written on the death certificate and long story short they had to get, they had the wrong thing on the death certificate and so that uhm, they had to get the wrong thing removed and it took a long time for the mailing process to get in, but that situation really effected the family because they felt like first their dad, they couldn't grieve the way they wanted to because they felt like they had a lot of anger with that situation, and they could properly heal and that's the down thing because they were waiting for a good month or two months uhm, to really heal to really grieve but they had so much anger and frustration with that situation that it took them that much longer to really get through that and to let that anger go and to just be there to support each other because they all, all the members have their individual grief, but it took a while and as a counselor I think it's hard to help a family process things when they feel like things are not getting done and then you try to help them with that process but they just can't get past the initial anger, so I guess that's the down because I think it's always a hindrance to start grief a month or two down the line as opposed to kind of tackling it in the beginning and the healing process starting from there.

Participant B. This participant talked about a case where a patient stopped breathing and as they walked in with another family member the patient took their final breath. The participant felt as though it was somewhat of a miraculous experience and a testament of their faith.

>Okay, I went to visit a pt., it was actually the same time I was going to see the pt. and I got on the elevator with a young woman, my age or younger, and we were going up and I said where are you going and she said to see my aunt and I said is her name xxx and she said yes, I said okay we will go together, and we got off the elevator, walked into the apartment and uhm, the other niece was there as was a continuous care nurse and the other niece says oh look xxx has come, and the pt. drew a spontaneous breath and let it out and that was it, now the backstory was before we got into the apartment the pt. had stopped breathing we got there and I'm assuming between a minute or two and the other niece said what she said and the pt. drew a spontaneous breathe and let it out and that was it, that is the one most memorable, most of the time uhm, the deaths that I see are good deaths, pts just slowly stops breathing, it takes a moment for everyone to realize the pt. is gone, I have been there when the pt. is calling out to someone or looks like they are reaching out to someone, I haven't had anyone tell me they see the white light but that one situation was the most memorable.

Participant C. This participant gave details about a case where a father was dying and he
was not in communication with one of his sons. The son was abroad and
managed to come and sit at the bedside of the patient as he took his last breath.
The participant viewed this experience as one of healing which rekindled a
dysfunctional family and affirmed their faith.

> I also recall a particular case that was very interesting it was an older man
> that the doctors the nurses even the family couldn't understand how he
> was still alive because he was declining so rapidly the doctors talked
> among themselves they couldn't explain what was holding him so one day
> his son told me that he thought his father was waiting to hear from the
> other brother that left twenty years ago and they didn't know where he
> was, so the next day he was so excited and he wanted to talk to me and tell
> me that last night my brother called us, he's in Canada when we told him
> about our dad he said that he was going to come and we told him that
> probably he will not have time to come to get here, so, it took about 2 or 3
> days for the brother to come from Canada and finally he came and I
> remember I was in the room when he came directly from the airport, and
> he took himself to his father who was comatose and asked him for
> forgiveness and he started crying, and we saw the patient, there was tears
> coming out of his eyes it was a very intense moment so I was trying to
> calm down the family and I told them now look he sensed him, our sense
> of hearing we don't lose until the last moments and the brother said no,
> you don't know, my dad, in Vietnam loss both ears, he could hear he was

official and totally unable to hear because of the explosions of the bombs

during war so I said you see it's a sign that he knew that the brother was

with him and he forgave him and this would give peace to your brother

because it was reconciliation at the last minute, this was a touchy situation,

it happened about 4 years ago and when I remember it I still cry.

(Participant teary) (Silence)

Participant D. This participant gave an account of a woman with brain cancer which

caused her to react like a child. Her mother was having difficulty adjusting to the

affects the illness played on her daughter's persona. The participant discussed the

way the mother of the patient wrestled with her faith and asked God for a sign.

The participant referred to this case as miraculous.

Yes, for example I know, I met a lady . . . she was around 33 years old and

she had a brain tumor . . . she became like a little girl, and she used to play

like a girl and talk like a girl and she forgot completely that she had

children and she had only 1 girl, she was all the time like a baby, asking

chocolate, asking for toys and everything and when she was declining her

mother was a very faithful person and when she was almost dying she was

like very overwhelmed and moving her house and everything and she

awakened and her mother asked her what happened with you and she told

her mom Jesus is calling me there are some children dressed in white and

they are calling me and the mother told her you can go, and she said but

over time what is going to happen with my daughter and she was talking

with her like a woman and you know, she said don't worry about your

daughter because as I raised you I am going to raise her I am strong and I

can do it don't worry go in peace don't be afraid if Jesus is calling you

then go with him and then it was like palm Sunday and she died when her

mother was doing the holy rosary on black Friday at 3 o'clock at the time

when Jesus is supposed to die and she told me father I was asking God for

a sign about my daughter because you know we are human beings and

sometimes I was thinking about it she was my only daughter and I was

weak in my faith and I told him Jesus give me a sign that my girl, my

daughter is alive and that is the most beautiful proof she died on black

Friday at 3 o'clock and I was there I was a witness of this, that's very like

you know very good for me because it was painful but at the end it was

like I was grateful too because it was like a to see like a miracle a sign.

Participant E. This participant described discomfort when family members do not

provide privacy and sensitivity toward dying patients.

. . . as a matter of fact there was. . . there was this poor man that was

actively dying also and I went, I go to their apartment this poor man, they

had made room for him like in the living room, they had sectioned off a

piece and they he was lying in the bed and there was like all these women

in there the daughter the wife the grandma I don't know so many women

and this poor man had had ah, ah, I don't even know what to call it . . . I

had gone with the nurse because during that time sometimes I worked with

the nurses I go into these homes with nurses and this poor man was

actively dying and apparently he seemed to have gotten an erection . . . so

you would think, you would think this family would you know consider

the privacy of this man, you know, and all of a sudden all of these women

are sitting around the bed looking at him and they said come over and I

said no I will sit over here and you know you guys stay there and you

know why would you know this poor man who was dying why would you

be around his bed looking at his penis why you know I don't understand

some people it's like crazy stuff you see sometimes and unfortunately you

are a part of it and you don't want to be a part of it it's like you are trying

to support the family and you get caught into this mixture of just you

know weirdness I don't know, so yeah those kinds of crazy stuff.

Participant F. This participant gave two examples of cases that played an impact in their

life. The first case revealed the comfort a patient and their family received from

their spirituality. In the second case the participant was humbled by the kindness

of a dying patient.

Interesting let me see which one, I don't know all of them, because it

depends on the person and how they deal with death, their spirituality, the

way they have to deal with daily situations, it has to be with so many

things that I have a lot of you know . . . I have another one with a woman

who died of cancer and she had 2 kids too but she was from a very

spiritual family with very spiritual beliefs and the way they coped with

this situation really impressed me it was extraordinary how their faith

helped them go through, also I had this case another patient that died of

this strange illness that caused him pain all over his body all the time it

was a very strange case and he was so strong and I learned so much from

him, I went to see him and he cares about me it was incredible.

Influences of Spirituality

After continued examination of the transcribed interviews the role of spirituality

was revealed in 6 out of the 6 participants. 5 of the 6 participants viewed spirituality as a

tool for providing comfort, either to themselves or the patient-family units they served. 1

participant, Participant D objected to the use of spirituality within the context of the job

stating, ". . . spirituality should not play a role in the context of my job at all and I try not

to bring it in either I don't think it should be there."

Participant A. "Well spirituality plays a major role well I plays a major role in

how I see death in my job for some of my families who aren't spiritual it

doesn't play a major role for me helping them because I feel I have to a

different perspective for families who are not spiritual at all, it's easier for

me to play that role when I am dealing with a family who is spiritual or

religious and help them heal through it that way but uhm, me personally it

helps me out a lot, but I can see in this job how your spirituality or religion

can be shaken a bit when you're losing someone especially someone you

lose unexpectedly or you wonder why they had to go through the pain that

they went through, so I would say spirituality does play a major role

because a lot of times I deal with a lot of families that are spiritual and

then after losing someone their spirituality is shaken where they have a lot

of anger through God and so then you have to kind of help them process

that anger and really normalize that anger for them, and so I guess I plays

two roles it can be a healing role for some families in which way I guide them in that or it could be a very damaging role when it comes to the families and their spirituality and the role I play in that is just normalizing it for them and letting them know it's okay for their beliefs to be shaken and you know they have to kind of take it upon themselves to see if they want to rebuild that spiritual guidance or if not."

Participant B. "Okay I personally find it difficult to separate spiritual from religion cause it is part of my religion I do realize that there are people who look at the religion as spiritual or as religion as a spiritual thing yeah, okay, I had a patient in Hollywood, who was dying and he had 2 sons and a daughter and the wife was catholic, the wife was very nice, she was, she had her faith to fall back on but she appreciated the fact that her husband was (a different faith) . . . I was there for her children if they needed the daughter who was the youngest child had a very difficult time, she was concerned that A. her father would be in a dark place and not know where he was and B. he would be alone and that C. he would not know where she was he would not see her, it took a long time but I was able eventually to get her to see that uh, death did not leave her father in a dark place, that he would in fact be in a good place and that there would be others with him, family, friends, neighbors, whoever had gone before they would all be there with him and welcome him and make him comfortable and he would not be alone and that yes he would be able to see her and he would watch her, and she might not know it but he would be there and he would take

pride in everything that she did and the way she conducted her life, it took

a few hours but ah, I was able to eventually get her to see it."

Participant C. "In a way it (spirituality) does because now when I see someone

that is sick regardless if they are in hospice or not I could be visiting

friends at the hospital I not only see a sick person but I see a person that

probably is in need of spiritual support also, I'm more aware of the needs

that the family may have in that particular moment."

"Well that is the basic role I mean without spirituality I would not be able

. . . to do work, regardless of their own personal beliefs."

Participant D. "Oh yes of course it (spirituality) has to it has to play a big role

because of my job . . . and I believe in God and I believe in life beyond

death and spirituality is probably very important in my life because

sometimes when I realize that I am worrying I realize that I discover

myself going back in my spirituality when I don't have time to do my

prayers to meditate to reflect on my life bout God about me when I don't

have the opportunity to praise God before my life I am going back but I

think spirituality is the most important, spirituality and emotional things

are very important in my life."

Participant F. "For me I think all the time, all the time because spirituality is so

important when you are facing death and every person has different beliefs

that we have to respect so I just support them in every belief because I

think that the strength that you disperse from spirituality is a great help for

families and even for me that I am you know dealing with every day."

Stressful Aspects of Working in Hospice Settings

Six out of 6 participants identified stressors working in hospice settings. Stressors included working with death, dysfunctional families, and commuting between patient-family units.

Participant A. "The stressful aspects I would say is when the families are in denial and not accepting towards the death or when the spouse that is still living is going through a lot of depression and they can't see a positive or they can't see the light at the end of the rain, they are just stuck in their depression and stuck in their grief and I would say that that is the most challenging dealing with denial and depressed clients."

Participant B. "Death, that is probably at the top, dysfunctional families can be difficult although I really haven't had to deal with it, families that are not finding the proper outlet for their grief, whatever that may be, they may be turning to other outlets and that would not necessary in the long run help."

Participant C. "Well, to be facing death almost every day . . . and I work full time here, so constantly I see people die, some people even pass away when I am holding their hands or the family is present and that is totally, you don't get to use to it because each experience is a different experience."

Participant D. "Well some people are dying and the family is not coping well when the family is not accepting when they are in denial and I have to support them. . . I feel like a little bit frustrated because it doesn't matter

if you say too much words to those who are suffering they don't find

consolation at that time so it's a little bit stressful to me."

Participant E. "I think some of the stressful aspects of my job is the driving

around in this traffic you get a lot of stress with having to have eyes all

over the place and on top of that families can be very overwhelming when

you get there because of the grief . . . and on top of that I have been even

asked questions how long do you think she should live and what do you

say to that I don't know how long your mom has we don't know that, well

if I knew she would be alive 10 years I would have never put the feeding

tube in, so these comments that the family make really stress me out

because it's very difficult to answer them when they ask questions or

make comments like that."

Participant F. "Okay, I think that mostly it's the driving."

Methods of Coping with Job Related Stress

There were 6 out of 6 participants that identified coping strategies they utilized

working with stressful cases.

Participant A. "Uhm, I go home and I watch reality TV."

"If it wasn't for me having a good relationship with certain coworkers and

being proactive and feeling comfortable talking to them about it I would

really probably deal with a lot of it on my own because you know you

can't talk to family members about it because of confidentiality. . . ."

Participant B. "Well I go home and kick the dog, (laugh) . . . I will bury myself in

some mindless television or read a book to totally get my mind away from

where I've been all day, I look forward to James bond film festivals so I

can just veg out for a couple of hours uhm, it I don't know why but it is

not very hard for me to move from one compartment to the next maybe

it's a psychological thing maybe it's hardwired in my brain and I don't

know but I find it relatively easy to be able to switch gears so after a day

like the one I described to you I will sit on my bed and find a book or turn

on the TV and find something mindless that I can just stare at the TV or

maybe even take a nap I just try to switch gears as much as I can."

". . . there are counselors that I could go to if I felt myself in the need,

there are psychologists, social workers, I have my world of (spiritual

leaders)."

Participant C. "Well, I try to move to finish my daily work I'm also working in

my (spiritual place), there I have different tasks working with different

groups so it is kind of a change of environment, I also like to take trips

inside of the area, that also helps me so that's the way I do it."

Participant D. "Okay, my prayers, every day I try to take time to reflect to

 meditate about my job about myself about my family about my society

about what is my function, my functions or my mission over here and I

pray my whole is before God and I think when I put all those things before

him I receive I receive the grace and the mystery of God, a wonderful

support."

Participant E. "The way I deal with stress from my job is I get home I feed

(animals) and I sit in front of my TV to watch TV until I feel like I'm

already relaxed enough that I can get up and just continue doing whatever

it is I need to do around the house."

"I wish we had programs that would help us . . . we are stressed out. . ."

Participant F. "Uhm, I talk with colleagues about how I feel."

Utilization of Researcher's Journal

The utilization of a journal provided an outlet for the researcher to express the

impact each of the interviews played in creating a shift in perspective. The researcher

noticed three overall themes emerge from journal entries; a connection with the

difficulties surrounding cases, a shift in perspective from an inability to cope to a

renewed understanding of the critical role spirituality played, and the significance of a

journal to process the emotionality of working with patient-family units exhibiting

anticipatory or complicated grief.

The researcher noted difficulties surrounding cases as therapy entailed, "the raw

emotions that you are exposed to when working in this setting" and "candid descriptions

of pain." The researcher realized a shift in perspective, ". . . in our humanness we face

similar situations, similar reactions, and our outcome is dependent on our spiritual

perceptions" and "The beauty spirituality give us to know that there is a life after death

where this physical body that seems to let us down, that has and ultimately will fail us

perishes but that the center of our being, what some may call our spirit or mind, will have

an eternal life provided me with great consolation." The researcher also expressed the

process of capturing their emotionality through journaling, "Realizing my own mortality is something that has changed the way I view each day, it guides my thoughts and actions because now I know how life can go in an instant." The journal provided the researcher with a self-reflective analysis of the depth of meaning derived from each interview.

The Researcher's Journal served as a tool for the researcher to capture thoughts and biases related to each participant's interview. In order to reduce researcher influence over participant answers, the researcher decided to ask all participants the 20 interview questions without asking follow up questions. This allowed the participants to respond to each question without additional inquiry, which may or may not have persuaded participant responses. Additionally, the researcher analyzed the Researcher's Journal after analyzing the data from the participants. This allowed the researcher to capture the essence of the phenomena from verbatim interview statements from the participants.

Summary

In this chapter, the parameters at which the researcher conducted the research and the findings of the research were discussed. The findings captured the meaning of the experiences of working in a hospice setting and the translation of those experiences into shared meaning about death, trauma, and loss. Participants also gave vivid descriptions of cases that impacted the way they interpret death, trauma, and loss. The role of spirituality, workplace stressors, and methods of coping in hospice settings were also discussed along with the utilization of the Researcher's Journal.

CHAPTER V: DISCUSSION AND IMPLICATIONS

Hospice care continues to be a supportive measure to ensure proper biopsychosocial-spiritual needs of the patient and their family is met. The provision of care does not come without the patient and the family realizing the factors surrounding the terminality of the illness and recognition of the patient's fatality. Though several research studies have shown workplace stress Hospice employees endure, none have explored the meaning Hospice employees derive from working through anticipatory or complicated grief narratives. Therefore, the researcher chose to conduct a phenomenological study to generate collective meaning of death, trauma, and loss from Hospice employees whose primary role was to work with patient-family units exhibiting an inability to cope with factors surrounding end-of-life.

The research question for this phenomenological study was "What meaning do HBCs ascribe to their experiences of death, trauma, and loss working in Hospice settings with patient-family units exhibiting anticipatory or complicated grief? By answering this question the researcher hoped to generate factors that contributed to the overall perceptions of their experiences, identify stress influencers, and uncover coping strategies. The essence of lived experience from all participants appeared to reflect five elements of the phenomena.

Essence of the Lived Experience

The first element highlighted was the conflicting nature of anticipatory or complicated grief with the participant's interpretation of death and those of patient-family units. As Kübler-Ross and Kessler (2005) explained anticipatory grief was the process a patient may experience as they process their terminal illness and start to mourn their

death. Complicated grief was a result of an inability to make meaning of life without the person (Neimeyer, 2005-2006). A paradox developed as the participants viewed anticipatory or complicated grief as a confusion or lack of understanding in the natural process of dying. Participants felt without being grounded in the nature of death and its natural process, patient-family units exhibiting anticipatory or complicated grief were caught in the content of their experience which served as a distraction from the situation they faced. All participants viewed death as an inevitable physical end for the body and a transition of the soul.

The second element acknowledged loss as the next stage for survivors of the deceased. Participants viewed loss as a new way of learning how to live a life absent of a person who once occupied a physical body. Loss was observed by participants as a time that created family dysfunction and uncertainty for those who displayed signs of anticipatory or complicated grief. Participants described loss as an inability to come to terms with the reality that the person who once shared space and time with them no longer possessed a physical body. Participants viewed loss as a start of something new, the beginning for survivors of the patient to incorporate their lives through memories. Participants also believed that families with a strong sense of spirituality suffered anticipatory or complicated grief less. They attributed this reduction to the comfort patient-family units found through the consolation of their belief that their loved ones were going to a better place and they would one day be reunited with them.

The third element uncovered was the instability patient-family units exhibiting anticipatory or complicated grief faced. Instability was due to the impending death of a loved one and the circumstances surrounding the uncertainty of their physical death.

Families with symptoms of anticipatory or complicated grief were not sure when the patient would take their last breath and due to a lack of faith patient-family units viewed their last moments as an end to the patients being. Participants felt that families facing difficult medical decisions were also in a state of instability as they struggled to make rational decisions that were based on the patient's quality of life and not their personal desire to hold on to the patients ailing body. This statement supported a previous study as Finucane (1999) attributed this preoccupation with their loved ones impending death as one of the difficulties surrounding end-of-life. Participants in this study went a step further to attribute this hardship to a lack of faith or spiritual guidance. Participants thought patient-family units displaying strong spiritual beliefs refocused their attention to a spiritual life absent of a body which provided consistent stability. In cases where spirituality lead to the belief that death was the final stage of life, topics of unrest or concern to the patient or family were addressed to provide resolution.

The fourth element of meaning was the constant reminder of faith and spirituality. Participants discovered being in an environment with constant reminders of death, trauma, and loss contributed to self-reflection with their own mortality. Participants exposed the difficulty they encountered working with anticipatory or complicated grief narratives as a constant reminder of how "real" death was and the devastating effects it can have on families. The uncertainty of dying became a real experience for participants and one that renewed their faith in a higher power. The reliability on faith provided comfort to participants as it served as a tool to explain the unexplainable and strengthened the possibilities of a life without the elements of a deteriorating body.

Although the questioning of one's mortality was apparent, participants felt a sense of peace as they relied on emotional support from their spirituality.

The fifth element of meaning derived was the proactive effort to create a balance between their work and their personal life. Participants showed the necessity to find a balance working in a high stress and high loss setting while processing grief narratives. Participants identified stressful aspects of their job and the need to develop strategies to combat the difficulties they faced. Whether the participant shared in the reunification of a family member, knelt at the bedside of a dying patient, witnessed a miracle or joined a family member to find a sense of peace, there were cases that were difficult for them to stop thinking about. These instances appeared to be typical struggles they felt were a part of working in the Hospice field.

The elements discussed were derived from the overall meaning participants expressed during their interview. The words participants used to describe the meaning they derived from their experience was unknown to the researcher prior to collecting the data, analyzing the verbatim transcripts, and generating themes for this research study. The verbiage became a part of the discovery in the process of formulating meaning from the transcripts. In addition, verification of the transcribed meaning by the participants provided validity in the conceptualization of the researcher's analysis and the messages conveyed by the participants.

Discussion of the Lived Experiences

This research study contributed to prior studies which highlighted the fear of death as a universal phobia (Peters et al., 2013). Participants in this study recognized their shift in perception from a fear to a natural acceptance of death's inevitability, as

Participant B noted ". . . it's more real." Participant D stated, ". . . when I started working here I learned how to see that death like is all things, I don't have fear . . . with my faith we live in this world but we are going to a better place. . ." Within a therapeutic setting death generated a conversation about one's spirituality as the participants felt ". . . it depends on the person and how they deal with death, their spirituality. . ." (Participant F) that faith changed a person's outlook from physical devastation to an eternal preservation. Spirituality addressed those who believed in a higher power and those who believed that there was no life after death. The therapist then engaged in meaning making conversations about what would need to happen for the person to feel a sense of peace. Spirituality gave rise to religious belief systems as well as a non-religious stance.

A prior research study suggested a need for the identification of elements of successful adaptation to bereavement (Dutton & Zisook, 2005). This research study found spirituality as a tool which provided successful adjustment to bereaved persons. Participant A asserted, ". . . I don't see death as final . . . they're not here physically but they are there spiritually . . ." another remarked ". . . life is not the end it doesn't end it's the beginning of a new life . . . God cannot stop creating . . ." (Participant C). Participants admittedly discussed their fear of death however faith assured them that it was merely a transition. Participants found that learning of a patient-family's faith allowed them to engage in therapeutic dialogue that shifted their attention from the patient's condition or their life absent of the patient to an acceptance that God is in control. Participant A noted, "It's easier for me to play that role when I am dealing with a family who is spiritual or religious to help them heal." Placing one's fate in faith provided a reassurance that the person was going to or in a better place.

As Melvin (2012) recommended the need to address effects of repeated exposure to patient deaths, participants in this study also noted constant exposure to death and family dynamics as identified stressors. Participant A discussed stressful aspects of their job as ". . . when the families are in denial and not accepting toward the death . . ." Participant B also noted family dysfunction, "death that is probably at the top, dysfunctional families can be difficult. . ." Participant C added, "Facing death almost every day" and Participant D mentioned, "People are dying family is not coping well when the family is not accepting when they are in denial." Participant E discussed the commute and working with families as stressful, "I think some of the stressful aspects of my job is the driving around in this traffic . . . that families can be very overwhelming. . ." and Participant F noted ". . . mostly it's the driving." Only 2 of the 6 participants in this study described being overwhelmed and stressed. As described in the literature review studies suggest these feelings as compassion fatigue. The low number of participants displaying compassion fatigue could be attributed to the heightened spirituality of the participants in this study.

Participants in this research study questioned their own mortality after repeated interaction with death, trauma, and loss. This complemented previous research studies which showed the difficulties surrounding discussions of end-of-life with patient-family units resulting in preoccupations with one's own death (Gazelle, 2007; Peters et al., 2013). The difference with this research study and others was that in this study participants viewed their own mortality as a natural outlook that one must acknowledge when they enter into a field where patients are given terminal diagnoses. Working with terminal patients allowed the participants to see themselves as they witnessed patients of

similar ages or from similar familial backgrounds at end-of-life. This environment shed light on the reality of death and forced employees to examine their own mortality. Difficulty healthcare provider's face when working with terminal patients was the reality that they too one day may face a similar diagnosis.

The constant reminder of the uncertainty of life created a renewed spiritual belief in a higher power. Participants discussed ways in which their spirituality played a role in allowing them to deliver the services required of them to fulfill their job responsibilities. Participant A noted "spirituality plays a major role." Participant B found it difficult "to separate spirituality," and Participant D expressed the role spirituality provided in offering consolation to the deceased, "I believe in God and I believe in life beyond death and spirituality is probably very important in my life." As Rolland (1994) expressed the prominent role "beliefs or practices" play in the process of dying, participants of this study contributed to his research in that they highlighted the role it played in the lives of HBCs and Hospice Chaplains.

The biopsychosocial-spiritual consequence of working with anticipatory or complicated grief was also revealed in this study. Unlike other studies that focused on the biopsychosocial-spiritual effects of illness on patients and their families, this study observed those effects on the clinicians that provided psychosocial-spiritual care to patient-family units. Participants discussed feeling "overwhelmed" and at times "really stress me out." Participants noticed themselves feeling fatigued and at times utilizing television as a means of engaging in "something mindless" or "take a nap . . . to switch gears" (Participant B). Participants also found that speaking with coworkers provided a psychological release. Participant F stated, "I talk with colleagues about how I feel" and

"having a good relationship with certain coworkers" (Participant A). Each participant found support from their spirituality. Participant D expressed "my prayers" allowed for "time to reflect to meditate."

Additional support for Hospice employees continued to be a trend. Research studies from the literature review section highlighted a need for adequate training (Eagle et al., 2012) and continuing education courses (Johnston and Smith, 2005). Solcum-Gori et al. (2011) stressed the importance of training programs that were tailored to address the biopsychosocial-spiritual aspects of delivering patient care for Hospice employees. Participants of this study embraced training programs and continued education classes offered through their organization. Participants also expressed the desire for single sessions to assist with processing grief narratives.

Limitations of the Study

The participants of this study were from one faith-based Hospice organization in South Florida. Consequently, the researcher's findings supported the important role spirituality played on providing answers to questions no one could answer. Spirituality served both as a coping mechanism and a driver of supportive care to participants. Spiritual influencers in Hospice employees not affiliated with a faith-based organization would be an interesting area for further exploration.

Researcher's Lived Experience

The researcher found a sense of belonging and support while conducting this research study. Listening to each participant describe their experiences with death, trauma, and loss the researcher began to feel a connection as they eloquently put into words emotions the researcher found difficulty expressing. Learning that participants

found themselves questioning their own mortality, provided a comfort as the researcher found they were in that situation and felt alone in this quandary. The constant reminder of the uncertainty of life created stressors for the researcher as well however, as a result of these interviews the researcher began to seek out spiritual guidance as a means of coping with all aspects of the job.

The loss of control was discussed throughout interviews. The loss of control over when and how death would occur created stress for the researcher who did not think prior to the interviews that a spiritual walk with faith could ease traumatic experiences. Additional support was needed to assist HBCs and Hospice Chaplains manage the daily stress of working with death and grief. Their proactive need to develop a balance between work and their personal life was admirable. As Charles-Edwards (2009) noted there was a need for creating balance in the workplace. Therefore, HBCs and Hospice Chaplains found themselves taking a proactive stance to engage in activities that allowed them to escape from the reoccurring thoughts that surrounded certain cases. The researcher had not realized that they too shared in some of the proactive measures participants described. The researcher wondered if proactive measures were also incorporated by the organization where they mandated one-on-one weekly sessions and quarterly group sessions if there would be a significant decrease in perceived workplace stressors.

The researcher's journal served a crucial role in understanding the biopsychosocial-spiritual aspect of each participant and the impact their interview had on the emotionality of the researcher. The journal could be a tool to show the compassion felt toward participants as they divulged the depth at which working with patient-family units experiencing anticipatory or complicated grief played in their lives. The researcher

was able to journal the experiences with candid remarks of the interpretive journey each

HBC and Hospice Chaplain shared. The reflections in the journal served as a tool to

develop a rich perspective of the total experience of conducting this research study.

Systems Perspective

From a systems approach the interpretation of the meaning derived from

experiences with death, trauma, and loss among HBCs and Hospice Chaplains showed

the effects of a "language-generating, meaning generating system" (Anderson &

Goolishian, 1988). The message from participants was the reward they received from

working with patient-family units who were experiencing the final stage of the physical

life and the honor to be a part of the transition of a patient into an afterlife. The depth at

which HBCs and Hospice Chaplains discussed their experiences could be seen as one of

"no longer separate, oneness acting upon each other" (Keeney, 1983). The soul or spirit

of a person transcends the body. It is as if the mind or the spirit of a person was set free

from their disease stricken body.

Biopsychosocial-Spiritual Aspects

The biopsychosocial-spiritual aspect of death, trauma, and loss could be viewed

as the disappearance of the physical mortal to one of immortality. As George Engel's

biopsychosocial model needs to expand into the systematic structures of healthcare

administration for their employees (McDaniel et al., 1992). The psychological aspects of

exposure to death, trauma, and loss were revealed through a need to create balance.

Proactive self-care measures by the organization could help to reduce some of the

complexities of processing difficult cases where Hospice employees may feel alone. This

would reduce the risk of compassion fatigue among HBCs and Hospice Chaplains who

do not wish to transfer their stress onto other co-workers who experience similar daily situations. As Solcum-Gori et al. (2011) noted, in their study, compassion fatigue was a result of constant exposure to death. Sociological aspects of cases such as similar age of the patient and the HBC or Hospice Chaplains or familiar family dynamics evoked stressors in HBCs and Hospice Chaplains. As they discussed relating to other cases more when these factors were present. Spirituality served as a guiding factor for the majority of the participants. All participants discussed the comfort derived from their faith or their spiritual path.

Medical Family Therapy Advocacy

The researcher believes Medical Family Therapists working in the field of hospice have a unique opportunity to work within the therapeutic realm with patient-family units and within administration advocating for both patient rights and respite care for HBCs and Hospice Chaplains. Acknowledging previous studies in the literature review of this study and the effects of working with cases of death, trauma, and loss without proper support led to patient dissatisfaction, compassion fatigue, and burnout. A Medical Family Therapist as an advocate could expand case conceptualization to the effects of repeated encounters with death on healthcare professionals, recognize compassion fatigue, and proactively reduce burnout in staff. The researcher noticed a release from participants as they relived experiences that were memorable to them. The opportunity to share cases that left an imprint in the minds of the participants showed genuine care and support for the challenges they expressed.

The majority of participants felt a calling to this profession. They felt as though they were delivering a service to patients and families by shifting their interpretation of

the transition from this life to another. They also reported that continually encountering death was sometimes overwhelming. Cases of compassion satisfaction to compassion fatigue may be a result of unstructured resources driven towards self-care. The questioning of one's mortality also gave rise to the experience of anticipating one's own death or thinking of one's own health. Through the internal dialogue many participants discussed having about their mortality seemed to create anticipatory grief about their own death, when none of them were currently faced with a terminal condition. Initiating a weekly group session with team members, monthly in-services about coping with grief and loss in the workplace, and quarterly training programs may help to reduce these stressors.

Intricacy of Traumatic Loss

Participants mentioned two other points of traumatic loss. The first was that of a family member witnessing the debilitating effects of a disease on their loved one and an inability to provide reprieve. It was the family's helplessness associated with watching their loved one grasp for breath, inability to eat, or listening to the sounds of uncontrollable pain. The second traumatic loss was that of losing a patient that the HBC or Hospice Chaplain worked alongside whereby the patient may not have been spirituality led. In this instance there was mourning on the part of the HBC or Hospice Chaplain as they were wrestled with their internal feelings guided by their faith.

Dynamic of Secondary Trauma

Some participants described secondary trauma as they described difficult cases of listening to emotional accounts of the pain family members discussed after the death of their loved one. These disturbing cases often left HBCs and Hospice Chaplains unable to

rid themselves of the narratives repeatedly playing in their minds; therefore, cases contributed to stressors indicated by the participants.

Personal Impact

Conducting this study has been a transformational journey both personally and professionally. The researcher gained a deep level of respect for their peers and other healthcare professionals working with chronic or terminal patient-family units. Their level of compassion toward caring for ill patients, their desire to create stability during uncertainty, and their willingness to provide empathy during difficult times was admirable.

In conducting this study, the researcher found a new way of approaching patient-family units. The researcher realized with each personal reflection of the interviews a new way of delivering therapeutic intervention unraveled. Relying on the spiritual component of the patient and their family meant the researcher could join patient-family units in a new type of dialogue. A conversation that did not seek solutions to unanswered questions or the ability to make sense of difficulties that many people face at end-of-life but rather seek to find how their spirituality defined death and loss. This type of conversation would allow the researcher to engage in a spiritual walk with both the patient and their family. Their view of a life after death or a life that ended in final death would shift the dialogue to one of fulfillment as the end of pain and suffering would soon subside.

The researcher decided to experiment with this new way of delivering therapy with patient-family units exhibiting signs of anticipatory or complicated grief. There was a case of a patient that was given 3 weeks to live. The patient battled cancer in the past

but as they took care of their spouse they neglected their own health. Their spouse passed way one month ago and the patient went for a checkup and found out their cancer spread everywhere.

The researcher met with the patient and listened as they described the loss of their spouse and the uncertainty that lied ahead for their children. The patient expressed concern about the welfare of the youngest daughter in particular. The researcher decided to ask the patient how they managed to focus on the well-being of their loved ones given the terminality of their condition. The patient noted that they had always cared more for their loved ones and that they are okay with their diagnosis, noting the end was near.

The researcher then inquired about the patient's spirituality and what they believed would happen when they passed way. The patient raised their eyebrows and tilted their head, they took a deep breath and expressed the power of their heavenly father's grace. The researcher and the patient engaged in a powerful conversation about how they were looking forward to being reunited with their spouse and that there was a heaven they looked forward to seeing. They also discussed the hardest thing which the patient identified which was saying goodbye and knowing they would not be with their loved ones physically to share daily life experiences.

The patient asked that the researcher invite family members to discuss their illness and open a dialogue about what their beliefs were about dying and how they wanted to be remembered. The family joined and it was a beautiful session as tears rolled down the faces of the family members and the patient said those tears are love and compassion. Had this research not been conducted the researcher would not have been able to lead this type of conversation as the fear of unknown questions or situations would have been

overwhelming. Instead, when the family member asked if the researcher knew when the patient would die, the researcher utilized their spiritual beliefs to answer "The moments we have now are to be cherished, no one knows the exact time when God will call (the patient) home, I can tell you they are ready" the researcher looked at the patient, they smiled and said "I am ready." The patient's sister got up and hugged the researcher whispering, "Thank you, you are right you are not God, he will come in his time, and we needed this."

As a result of this study the researcher found a need for healthcare providers to provide support to clinicians. The researcher developed and administered in-services for their current employer on identifying compassion fatigue and burnout with tools to combat the emotionality of the job. The researcher delivered in-services to multiple locations in South Florida. The in-service allowed the clinical employees to openly discuss some of the challenges they faced and identified difficult cases which prompted conversations about their process of coping while team members offered support. The researcher also conducted training programs with clinical staff at hospitals throughout South Florida on: Supportive services for bereaved persons; A systemic approach to death, trauma and loss; Signs of compassion fatigue and burnout; Healthy ways to reduce stress; and Advanced directives.

Future studies could include the transformative process of conducting research to include the stance of the researcher captured through journaling. Journaling by the researcher could provide additional background into the impact conducting these type of qualitative studies have on the researcher. Shared meaning of a phenomena could be

depicted through the use of journaling as the researcher joins with the participants in capturing the meaning they derived from their experience of the interview.

Implications for Future Research

Many of the research on Hospice employees have focused on quantitative measures to obtain results and interpretation of written surveys. While this is a viable option, the need for Hospice employees to tell their story is important. Future research should incorporate qualitative analysis in order to understand the meaning behind the experiences being tested.

Due to the limited number of participants in the study, a future research study could expound on this study by incorporating the social workers and crisis care nurses whose role is to be with patients who are actively dying at the bedside. This would allow for larger scaled training programs and self-care programs tailored to meet specific of team members according to their job duties within hospice settings.

Based on the findings of this research study there was a need to provide training programs that assisted HBCs and Hospice Chaplains discover ways to process experiences with which they felt they were struggling. Training programs need to be more specialized to address the individual needs of the targeted population (Eagle et al., 2012; Gazelle, 2007; Melvin, 2012). These training programs could reduce the level of stress by providing an outlet.

Implications for Future Practice and Training

While the research found in this study's literature reviewed the intensity of multiple stressors associated with working in a high stress and high loss environment, there was also a need to hear the voices from the employees within those settings. As the

researcher conducted the interviews, each participant acknowledged their appreciation and gratitude for being a part of the study. After further inquiry, the researcher discovered the participant's connection being in a confidential setting where their voices could be heard and their experiences shared. The face-to-face interviews prompted the researcher to understand the importance of providing single therapeutic sessions with Hospice employees as a viable coping option. Employees could then have a chance to discuss intimate aspects of their job which they may not feel comfortable discussing in a group setting.

Within the context of medical environments the researcher observed the tendency to disguise emotions about the effects of working with chronic or terminal patients. It was as if there was an unwritten rule that disclosure of true emotions would result in a person's incapability to carry out the duties they were assigned and trained to do. This type of shared engagement contributed to a new way of approaching cases that offered the researcher both comfort and confidence. Preparations for medical and mental health professionals during the course of their study and while in their professional setting to express and share their emotionality in a nonjudgmental confidential setting is needed. As the researcher explained how the study came to fruition with participants they expressed understanding of the complexities surrounding their Hospice experience. The researcher felt a richness and a bond form as their experience provided a new perspective for handling cases.

Therapeutic group sessions could be conducted prior to staff meetings that allowed team members to discuss complex emotionally disturbing cases, reflect on deceased patients while honoring their lives through remembrance narratives (a term

coined by the researcher to describe experiences shared with a patient or their family that evoked meaning in the Hospice employee), and reflections on cases that made them smile. Some groups could also focus on spirituality and the role it played in each of the employees mind. As spirituality played a major role to reduce anxiety, stress, and serve as a coping mechanism for participants in this research study there may be a way to assess spirituality prior to attending a group and then allow for an assessment after three or four sessions to track any changes the incorporation of spirituality may or may not have played.

Based on interviews the researcher developed round table psychoeducational programs for Hospice employees to begin a dialogue about stressors and coping mechanisms. The program provided a systemic view of the multiple roles each person plays and the importance of their ability to carry out their job duty in order to deliver patient-centered care. There was a continued need to create meaning generating programs or training for clinical staff in high stress high loss environments to share their emotionality. Their ability to express comfort or discomfort with cases could provide a release for them and would assist them in creating a work-life balance. When proper tools are placed for emotional offloading compassion fatigue may be reduced. This would allow participants to acknowledge their human tendencies and show continued compassion and empathy toward patient-family units.

Educational material on structured topics could be dispersed as voluntary reading for employees. Employees that decided to participate in reading a book, magazine article, and/or peer review articles could form groups and schedule a location and time to review lessons learned from the reading. This would continue to provide an outlet for Hospice

employees to share experiences. Scholarly articles could be found in the Journal of Social Work in End-of-Life & Palliative Care; the Journal of Marital and Family Therapy; and OMEGA Journal of Death and Dying. All of these reading materials could enlighten Hospice employees about current trends in research and serve as a platform to start conversations about self-care.

Summary

This chapter described the five essences captured in this study. The essences revealed how participants expressed feelings and emotions about working in high stress high loss environments. This highlighted their spiritual reliability and the powerful role their spirituality played in their lives. The researcher discussed the impact of conducting this study and implications for future research.

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Appendices

Appendix A

Definition of Terms

Anticipatory grief- a preoccupation with the loss of life prior to death.

Biopsychosocial model- refers to George Engel's incorporation of biological, psychological, and social dimensions of an illness into the medical field.

Biopsychosocial-spiritual System- refers to the idea that all problems are at once biological, psychological, and sociological with an interlay of spirituality (McDaniel et al., 1992).

Compassion Satisfaction- denotes educational rewards of caring for others in a health care context whereby clinicians feel a sense of return or incentive by seeing a change for the better in their patients and families (Slocum-Gori et al., 2011).

Complicated grief- categorized as chronic grief typically immobilizing a person from conducting daily routines with depressive characteristics.

Hospice- considered to be the model for quality compassionate care for people terminally ill; care is tailored to meet the needs of the patient and their family (NHPCO).

Hospice Bereavement Coordinator (HBC) - engage in emotional support to facilitate open discussions of coping with the declining health of the patient and remembrance of the deceased to reduce anticipatory or complicated grief.

Hospice Interdisciplinary Teams- professionals in Hospice consists of: physicians, nurses, pharmacists, social workers, chaplains, dieticians, bereavement coordinators, and volunteers (Parker-Oliver & Peck, 2006).

Medical Family Therapy- distinguished by its conscious attention to medical illness and its role in the personal life of the patient and the interpersonal life of the family (McDaniel, Hepworth, & Doherty, 1992).

Secondary Traumatic Stress- vivid descriptions surrounding the narratives of traumatic loss can create issues for clinicians as they absorb the impact of their work.

Self-care- denotes an ability to develop skills that maintain optimal psychosocial functioning

Traumatic loss- family and friends of a terminal patient fluctuate between an inevitable death and elusiveness surrounding the patient's expiration.

Appendix B

Letter of Intent to Catholic Hospice

Date

Contact Name
Organization
Address
City, State ZIP

RE: Uncovering Meanings of Death, Trauma, and Loss as Experienced by Hospice
Bereavement Coordinators: A Phenomenological Study

To Whom It May Concern,

I am a doctoral student at Nova Southeastern University in the Marriage and Family
Therapy program. This research proposal is to be submitted as partial fulfillment of my
degree plan. I have chosen this topic to identify the process that Hospice Bereavement
Coordinators incorporate to create meanings of death, trauma, and loss narratives of
patient-family units experiencing anticipatory or complicated grief.

This research will attempt to serve as a tool for capturing the essence of the phenomena
of working with dying patients and their families. I wish to request your assistance to
allow participants to have an opportunity to participate in this study. My goal is to have
participation from Hospice Bereavement Coordinators and Chaplains. It is my hope that
the analysis of this research of Hospice Bereavement Coordinators and Chaplains who
work with multiple losses and death will serve as a tool for clinical Hospice team
members to reduce stress and compassion fatigue in hospice workers. The information
needed to complete this study will be gathered by means of a one and a half hour
interview. Interviews allow the essence of the death, trauma, and loss to uncover.
Transcription of the interviews allows the researcher to develop themes that emerge from
and within the experience of death and multiple losses.

Should you agree, I would like to reach out to your Hospice Bereavement Coordinators
and Chaplains, I would provide you with the letter I will send to them via e-mail
informing them of the research study, an outline of confidentiality and forms to be signed
as consent for participation.

Thank you for taking the time to read this letter. If you have any questions, please contact
me via e-mail at rclarke@catholichospice.org or telephone at 954-593-3228.

Respectfully,
Rochelle S. Clarke

Appendix C

Letter of Invite

YOU ARE INVITED TO PARTICIPATE IN A RESEARCH STUDY: Uncovering Meanings of Death, Trauma, and Loss as Experienced by Hospice Bereavement Coordinators: A Phenomenological Study

Dear Potential Participant,

I am a doctoral student at Nova Southeastern University in the Marriage and Family Therapy program. This research is part of my partial fulfillment of my degree plan. I have chosen this topic to identify the process that Hospice Bereavement Coordinators and/or Chaplains incorporate to create meaning from patients and families experiencing anticipatory or complicated grief. Having had the experience of working at a faith-based hospice, I recognize the need for Hospice Bereavement Coordinators and others such as Chaplains to identify strategies and engage in conversations about experiencing loss. I experienced the need to make sense of some of the situations I encountered from losing a patient and working through the devastation of losing a loved one with family members. It is anticipated that this research will capture the experience of working with patient-family units exhibiting anticipatory and/or complicated grief and the process participants utilize to manage their job responsibilities. This letter invites you to take part in this study.

The study will involve you (the Hospice Bereavement Coordinator and/or Chaplain) signing consent for the study, a one and a half hour interview face-to-face, followed by the option of reviewing analysis of the data collected via e-mail within three days to gather comments and feedback. You are able to withdraw from this research at any time without reason.

Thank you for taking the time to read this letter. Please review attached consent form as well. Should you decide to participate please contact me via e-mail at rclarke@catholichospice.org or telephone at 954-593-3228 to schedule a time to meet.

If you have additional questions please feel free to give me a call at 954-593-3228.

Respectfully,
Rochelle S. Clarke

NOVA SOUTHEASTERN UNIVERSITY
Institutional Review Board
Approval Date: JAN 2 6 2015
Continuing Review Date: JAN 2 5 2016

Appendix D

Institutional Review Board
Approval Date: JAN 2 6 2015
Continuing Review Date: JAN 2 5 2016

NOVA SOUTHEASTERN UNIVERSITY

Consent Form for Participation in the Research Study Entitled
Uncovering Meanings of Death, Trauma, and Loss as Experienced by Hospice Bereavement Coordinators: A Phenomenological Study

Funding Source: None

IRB protocol #_____

Principal investigator
Rochelle S. Clarke, M.S.
775 SW 148 Ave. #1610
Sunrise, FL 33325
(954) 593-3228

Co-investigator
Tommie V. Boyd, Ph.D.
3301 College Avenue
Fort Lauderdale, FL 33314
(954) 262-3027

For questions/concerns about your research rights, contact:
Human Research Oversight Board (Institutional Review Board or IRB)
Nova Southeastern University
(954) 262-5369/ Toll Free: (866) 499-0790
IRB@nsu.nova.edu

Site Information
Catholic Hospice
14875 NW 77th Ave, Suite 100
Miami Lakes, FL 33014

What is the study about?
You are invited to participate in a research study. The purpose of the study is to identify how Hospice Bereavement Coordinators experience and create meaning of death and multiple losses while working with patients and families exhibiting anticipatory or complicated grief.

Why are you asking me?
The researcher is inviting you to participate because you are a faith-based Hospice Bereavement Coordinator and/or Chaplain currently employed at Catholic Hospice, located in South Florida, in a role providing therapeutic support to patient-family units coping with anticipatory or complicated grief. You have six months or more of experience working with patients and families who have experienced anticipatory or complicated grief.

Initials:_____ Date: _____   Page 1 of 3

You have experience with losing multiple patients in a Hospice setting; and you have the ability to meet for a one and a half hour interview with the option of meeting for a forty-five minute review of transcribed data analysis. You are English speaking and you are over 18 years old. There will be approximately 6 participants in this research study.

What will I be doing if I agree to be in the study?
You will participate in a one and a half hour audio-recorded face-to-face interview with Mrs. Clark. Mrs Clark will ask you about your interpretation of death and loss as it relates to working with patient-family units experiencing anticipatory and complicated grief; this is to capture the essence of the collective lived experiences. Interviews will be conducted in a private and closed room located in the main office of Catholic Hospice at the time that is mutually agreed upon. Interviews will last approximately one hour and a half (90 minutes) to answer semi-structured questions. The questions will elicit factors that may be associated with the job duties to capture the emotional factors, psychological factors, and identification of the process of working in a high stress high loss environment. Once analysis is drawn from the interview you may choose to review it with the PI in order to offer any additional comments and clarification. This second meeting will last approximately 45 minutes and will take place at the same place as the first interview. This second meeting is optional and will not be recorded.

Is there any audio or video recording?
This research project will include digital audio recording of the one and a half hour (90 minute) face-to-face interview. This audio recording will be available to be heard by the Rochelle Clarke, the IRB, the dissertation chair, and committee members. The recording will be transcribed by Rochelle Clarke. The recording will be kept securely in a locked cabinet in Rochelle Clarke's home office. The recording will be kept for 36 months and destroyed after 3 years. Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be guaranteed although the researcher will try to limit access to the audio recording as described in this paragraph.

What is the danger to me?
Risks, such as psychological discomfort are minimal, meaning, the research requires the participant to recall experiences which may cause some distress. You have the right to reserve sharing information or discontinue participation from the research at any time without any penalty. If additional help is required, the researcher will provide you a counseling referral, however, you will have to assume full costs associated with the services received. Another potential risk is confidentiality. The likelihood of a breach of confidentiality is minimal as procedures are in place to secure information. Names will not be utilized, audio recordings will be transcribed in Rochelle Clarke's private home office in a password protected computer accessible only to Rochelle Clarke. All materials will kept in a locked cabinet.

If you have any questions about the research, your research rights, or have a research-related injury, please contact Rochelle S. Clarke at 954-593-3228 or via email at clarroch@nova.edu. You may also contact the IRB at the numbers indicated above with questions as to your research rights.

Initials:_____ Date: _____   NOVA Institutional Review Board   Page 2 of 3
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Are there any benefits to me for taking part in this research study?
There are no direct benefits to participants.

Will I get paid for being in the study? Will it cost me anything?
There is no compensation for participation, nor any cost to you.

How will you keep my information private?
Your information is confidential. The information gathered will be kept private. The researcher will not include any identifying information that will make your identity known. The interview transcripts will be secured in a file for the review of researchers only.

The information gathered will be kept in a locked cabinet in the PI's home office. The recording will be secured for 36 months and destroyed after 3 years. All information obtained for in this study is strictly confidential unless disclosure is require by law. This audio recording will be available to be heard by the PI (researcher), the IRB, the dissertation chair, and committee members.

What if I do not want to participate or I want to leave the study?
You have the right to leave this study at any time or refuse to participate. If you do decide to leave or you decide not to participate, you will not experience any penalty. If you choose to withdraw, all information collected from you before the date you leave the study will be kept in the research records for 36 months from the conclusion of the study and may be used as part of the research.

Other Considerations:
If the researchers learn anything that might add to information about being involved, you will be told of the information.

Voluntary Consent by Participant:
By signing below, you indicate that:
- this study has been explained to you
- you have read this document or it has been read to you
- your questions about this research study have been answered
- you have been told that you may ask the researchers any study related questions in the future or contact them in the event of a research-related injury
- you have been told that you may ask Institutional Review Board (IRB) personnel questions about your study rights
- you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the study entitled "Uncovering Meanings of Death, Trauma, and Loss as Experienced by Hospice Bereavement Coordinators: A Phenomenological Study"

Participant's Signature _____ Date_____

Participant's Name _____ Date_____

Signature of Person Obtaining Consent _____ Date_____

Initials:_____ Date: _____

NOVA SOUTHEASTERN UNIVERSITY
Institutional Review Board
Approval Date: JAN 2 6 2015
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Appendix E

Research Questions for Research Study Entitled
Uncovering Meanings of Death, Trauma, and Loss as Experienced by Hospice Bereavement Coordinators: A Phenomenological Study

1. What made you choose the Hospice field?

2. What are some stressful aspects of your job? (stress)

3. Tell me some of the ways you deal with stress from your job. (stress)

4. How would you describe loss in the context of your job? (loss and process)

5. Please describe a case in which you remember losing a patient. Be sure to describe elements surrounding your relationship with the patient, how you found out about your patient, and details of how you responded. (loss and process)

6. Has working with loss impacted the way you work with patients and families? Be sure to give details. (loss and process)

7. When you think about a stressful situation in the last month were you able to discuss it with anyone? How did it make you feel? (support)

8. Thinking back, has there been a time when you found yourself wrestling with thoughts of a case, could you describe in detail what happened? (trauma)

9. What was that like for you? (process)

10. You've probably had some interesting experiences with death; can you recall any of them? Give details. (death)

11. Are there some that stand out more than others, can you give details? (death and trauma)

12. Has your view of death changed since working here, if yes, how? (death)

13. Do you have balance between your work and your personal life, could you give details? (burnout)

14. How were you able to do this? (process)

15. What are your perceptions of death, trauma, and loss in the context of your job? (process)

16. Does it differ between the context of your work and your personal life? (process)

17. Do you attribute meaning from your experiences with death, trauma, and loss? Please give details. (process)

18. Are there services or programs created for you at work to help you process stress?

19. Tell me how spirituality may or may not play a role in the context of your job. (spirituality)

20. Has your spirituality changed since working at hospice? Please explain. (spirituality)

Appendix F

Researcher's Journal

Participant A

I could relate to many of the things Participant A was saying. I remember when I started working at Catholic Hospice; all I wanted to do was use my therapeutic skills and became frustrated when it did not quite flow as it once did when I was in a field other than hospice. I realized that it was not so much about being prepared with the use of a certain model as it was being present in the moment with each patient and family member and allowing my therapeutic skills to enter our conversation without premeditation. I could understand when the participant discussed the importance of not taking things personally.

The nature of working with dying people is to accept the raw emotions that you are exposed to when working in this setting. I too felt like my team members have supported me with difficult cases so, it was nice to hear that it is a resource for the participant. I wonder if my curiosity was initially stunted by the fear of what it might lead to at first. What is meant by this is the candid nature of descriptions of pain a person may be experiencing both physically and emotionally. It is the uncertainty of not knowing if you can cope with what is about to be revealed. It is an undisclosed fear of what therapeutic dialogue might uncover through stories, emotions, the process of letting go and allowing the nature of the illness to take over, and whether you, the therapist, will be able to protect yourself from going in too much which could result in psychological distress. It was as if to become curious might lead to opening yourself and becoming vulnerable or learning how to get through it while not quite knowing how to process the

stories revealed about experiences the patient chooses to discuss as they no longer feel the necessity to carry it with them to their grave. I could relate to initially being stunned then realizing how to re-story or reframe their experience so that they were somehow dissolved or at a point where they could find a resolve and pass in peace.

Participant B

Remarkable how spiritually lead individuals can find themselves questioning or wrestling with much of the same feelings and emotions that I have. It was as if I began to yearn for a deeper level of spirituality. The deep connection of realizing that we are all at the core human and in our humanness we face similar situations, similar reactions, and our outcome is dependent on our spiritual perceptions. I felt blessed to be in the presence of people like this, who work with dying patients and assist families from a place of spirituality where meaning is derived when there is a trust in a higher power which offers healing. The nonjudgmental stance at which people can take to ensure the dying can truly rest in peace.

The stressors of the job can really be guided by the functionality or dysfunction of the patient family unit. The death and family interpretation of the death and loss can stay with not just me but others in this field too. I was comforted to know that the struggles of disconnection lies within my colleagues as it normalized my internal struggles. Learning how spirituality serves as a consolation makes me what to walk a more spiritual path if it can in fact provide a sense of peace and healing. It relieves the pressure of feeling like you and the patient or family are in this alone, it is comforting to know that there is a higher power looking over us all and providing us with a way when there looks like there is no way.

Participant C

I could relate to the driving but I do not view it as a stressor, I appreciate it. For me, this is a time to unwind and process the details of a case and it allows me to get prepared for the next case. There are stressors when traffic causes you to fall behind, yes, but I look at it as there is a reason why I need to get to the next place a little later. I find that I feel less in control about things I once thought I somehow had control over, like traffic and time. I realize that death is merely the absence of a physical body. I found myself wishing that I had asked myself these questions before I posed them to my colleagues as the richness of each interview provides me with new ways of viewing situations. I was honored to know we have such dedicated people working alongside patients and families. The selfless act of self-preservation and the unfortunate reality of self-deprivation are all factors that one encounters working in this field. It was as if there was an off loading and in it a comfort came, knowing that we are not alone in this way of thinking and being.

Circumstances and emotions are relatable. The beauty that spirituality gives us to know that there is a life after death where this physical body that seems to let us down, that has and ultimately will fail us perishes but that the center of our being, what some may call our spirit or mind, will have an eternal life provided me with great consolation. The constant though of questioning our own mortality is another thing I realized that participants shared and this too has been the case with me. Realizing my own mortality is something that has changed the way I view each day, it guides my thoughts and actions because now I know how life can go in an instant. My patient's illness begins to be somewhat of a blessing in that it provides them with a window of which to make their

wrongs right and because of the uncertainty of life and death I live each day without leaving loose ends unattended to.

Participant D

This interview was like taking a class in the philosophy and practice of spirituality. The ability to work with dying patients and families created a faith and purpose in the participant's life. Working with the dynamics of family members and patients are difficult and the faith of the participant has given the questioning and words they use to serve as a pillar of comfort. It is as if working in this field is a call that one receives from a higher power.

There are countless signs and miracles revealed that allow a person to become renewed in faith and develop a stronger walk with their spirituality. I understood the concept of being overwhelmed. I am realizing that with each interview I am developing respect, admiration, and a bond with each participant as their process provides multiple ways that I too can cope. I gather that if you have faith when you encounter death fear will disappear and preparation to be with your maker will be the glory you look forward to receiving.

Participant E

In this interview we both laughed and cried. The interview questions served as a vessel to allow the participant to share in the journey taken as psychosocial guidance is provided to patients and families. I realized the missed opportunity of having social groups of others in similar kinds of work coming together to share their cases and the value of having a person to disclose the effects of working with cases of anticipatory and complicated grief.

I realized that the death of others can become compounded when we experience a loss in our personal life. I also found the necessity for organizations, like hospice, to give its employees the opportunity to off load. We could laugh about some of the uncomfortable situations we sometimes are placed into due to patient-family dynamics and how difficult it can be to disconnect. I realized that if we are not given recognition from our peers about the preservation we hold onto about the lives of our patients through their verbal accounts of legacy building we become filled with overwhelming sadness.

The patient and family losses a loved one and with our role in hospice settings, working with multiple cases of anticipatory or complicated grief we are left with multiple losses. Our patient's whom we, in what may seem like a short time, we have developed strong emotional bonds with have passed and left us with candid conversational descriptions of raw emotions without reserve. I learned that service failures on our end can contribute to the detrimental uncertainty that surrounds a family's ability to cope with death loss and trauma. I also realized that although the trauma of a person's life is revealed when we are truly present with them in their story secondary trauma can creep into us. I learned that not having a voice with which to discuss complexities of this job may result in compassion fatigue and burnout. Today, I witnessed a spirit of good will clinging on to hope by a thread. I am honored to have allowed that silenced voice to speak.

Participant F

There is a rapport building that has to happen when working with patients and families. At times it can be slow which might leave the person charged with providing support to feel like time is running out and there are other cases where connections are

made right away. The connections made right away can be formed when a person can relate to the patient by closeness in age, similar family dynamics, and depending on the patient's age especially if they are children, adolescents or young adults. I could relate when it was discussed that when a patient is dying and they are close to you in age their fatality, their situation can stay with you longer and takes a while for you to process it. It brings awareness to one's own mortality. I found myself thinking back to a case as the participant talked about difficulties they experienced working with a patient who was their age. I realized that this person too discussed their faith in a way that provided consolation and how their faith had been renewed when they could not provide themselves with answers. There is a profound role spirituality can play to resolve these things that we question.

Biographical Sketch

Rochelle S. Clarke was born in Queens, New York. At the age of 12 she moved to South Florida with her parents and younger sisters. She received her Bachelors of Arts in Sociology from Florida Atlantic University. She then pursued a degree in business and received a Master of Science in Human Resource Management from Nova Southeastern University. After working in the business field Clarke felt driven to pursue a field in therapy where she could assist patients and families cope with chronic or terminal illness. Clarke went back to school and received her Master of Science in Marriage and Family Therapy with a certificate in Family Systems Healthcare from Nova Southeastern University, Clarke continued her education. She then completed her coursework toward her Ph.D. in Marriage and Family Therapy at Nova Southeastern University.

Mrs. Clarke is a Registered Intern with the State of Florida and is currently employed with Catholic Hospice as a Bereavement Coordinator where she delivers therapeutic support to patients and families exhibiting signs of anticipatory or complicated grief. Clarke has begun to deliver training programs to local South Florida hospitals on the importance of self-care, warning signs of compassion fatigue and burnout, and the need for healthcare workers to decide for themselves and open a dialogue with patients about advanced directives and end-of-life care. Multiple groups have been spearheaded throughout South Florida to support bereaved members of the local community. Establishing groups and/or in-services with Florida Medical Center, Plantation General Hospital, Mount Sinai Medical Center, and a variety of assisted living facilities and nursing homes, Mrs. Clarke provides both healthcare professionals and

patient-family units with education about death, grief, loss, and trauma fostering participant interaction.

Clarke has been invited to present at AAMFT's National Conference in Portland, Oregon and the Solution-Focused Brief Therapy Association's Conference in Toronto, Canada on "(SFBT) Relational Backpacking for Family Journeys with Autism" highlighting the journey families with a child with autism face throughout phases of life and techniques therapists can utilize to identify strengths within the family.