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Taking Care of the Forgotten:
A Pastoral Response to the Hospice Care Professional
By: Constance Friebohle
Integration Seminar, Spring 2019

St. John's University
School of Theology
Dr. Jeffrey Kaster

Introduction:

“Being a hospice nurse is described in research as a complex and multifaceted role with large amounts of complex emotional exposures.”¹ Being with those who are dying has an underlying component of trauma. This trauma when left to linger in the mind, body and soul of the hospice care professional causes harm. Pastoral care providers bring spiritual care to the dying and the family and friends of the dying. Who is bringing pastoral care to the hospice care professional? The research indicates that our hospice care professionals’ spiritual needs are being forgotten. Caring for the dying is traumatic for the hospice care professional as well as the family and friends. It is imperative that we provide a pastoral response to the spiritual needs of hospice care professionals.

Descriptive Empirical Task

Evidence from research will show what has been done to study how trauma effects nurses and professionals that work in the end-of-life field. Hospice care professionals’ benefit when given the opportunity to debrief. Personal interviews with Ten members of interdisciplinary hospice teams from the central Minnesota area were used for gathering data. These interviews were conducted in person and on the phone. The demographics of the participants are limited due to the small sample size and the location. Research from the Department for Professional Employees fact sheet from 2013 indicates some changes in the demographics for professional nursing staff. In 2012 90.6% of RN’s were female and 9.4% male. This is a rise of 2.5 % from 1995. Most of the RN’s are white, non-Hispanic, around 75%.² The demographics of my

¹ Ingebretsen, Lina Paola, MSN & Mette Sagbakken, PhD. International Journal of Qualitative Studies on Health and Well-being. Hospice nurses’ emotional challenges in their encounters with the dying. June 1, 2016. 1-13.

² Fact Sheet, Department for Professional Employees. *Nursing: A Profile of the Profession*. AFL-CIO. 2013.

sample n=10, 9 female and 1 male team member, all Caucasian, two administration, two social workers, two chaplains and four nurses and or certified nursing assistants (CNA's). The purpose of the interview was to help understand what is being done for debriefing and if the team might consider it valuable to implement a scheduled weekly or monthly debriefing session. See Appendix iv for the interview questions. The research delves into academic research papers and journal articles in academic journals to understand what is currently being valued in hospice care. The research department for National Hospice and Palliative Care Organization (NHPCO) responded to the question of debriefing by stating, "research in the area of hospice is being done but has not been completed for publication."³ The resources provided by NHPCO were valuable for understanding the benefit of debriefing to nursing staff. A clinical study done at Johns Hopkins Children's center; Baltimore Maryland collected data over a three-year period. Self-report evaluations show that these professionals found the sessions helpful.⁴

A social theory that explains why death causes trauma is explored. The theory used is called Terror Management Theory (TMT) and is intriguing and thought provoking. The findings of this theory and how it impacts the lives of our hospice care professionals will be unpacked. Following the use of a social theory one turns to the scriptures to understand how Jesus experienced death. What does Jesus do when he is confronted with Lazarus' death? In John 11:35 Jesus wept. Commentaries are used to see what the understanding of weeping might mean for Jesus. Jesus shows us the way to react to death. How does this impact the narrative of the lived experience of a hospice care professional? Jesus stood in solidarity with Mary and Martha

³ <https://www.nhpc.org>. the link to the National Hospice and Palliative Care Organization.

⁴ Keene, Elizabeth A.; Nancy Hutton; Barbara Hall; Cynda Rushton. *Bereavement Debriefing Sessions: An Intervention to Support Health Care Professionals in Managing Their Grief After the Death of a Patient*. *Pediatric Nursing*/ July-August 2010/Vol.36/No.4. 185.

as they wept at the loss of their brother Lazarus. Just as Jesus showed us a lived experience of grief, we now turn to theology to find definition in the church and how working in the hospice field might impact our brothers and sisters. How must we as pastoral people respond to their needs? The work of Ronald Rolheiser's theology of the Incarnation is explored. *The Holy Longing* written by Rolheiser explores the incarnate being within each other to understand and know that we are created in community and in that community of faith we begin and have being. And finally, a pastoral response is provided that may be utilized by all hospice teams for debriefing. The author hypothesizes that if one were to follow a team over time utilizing this pastoral response that by using a pre-survey and post-survey methodology one might find that this debriefing is valuable to the spiritual health and growth of the team.

Research has found that providing debriefing, a time to discuss the death or loss of a client and its effect on the hospice care professional, has been valuable.⁵ The research indicates that management is not sure how to provide intentional debriefing, nor do they understand it as a priority for formalized debriefing vs. organic. According to Eileen R. Sudecks'⁶ research in 2012, this was a contributing factor that caused the young and less experienced nursing staff to leave within a short period of time after hire. Sudek indicates in her research that contributing factors to compassion fatigue are closeness to the death experience, sadness of loss, over-attachment to patient and family, and viewing the prolonged struggle families experience with

⁵ Ibid. 185

⁶ Sudek, Eileen R. *Exploring Compassion Fatigue Among Members of the Interdisciplinary Hospice Team*. Thesis research study, Long Beach, California: California State University, School of Social Work, 2012. Research indicates that stressors outside of work such as societal attitudes towards death and dying create more stress for the nursing staff (34).

end-of-life issues.⁷ Protective factors that contribute to compassion satisfaction are self-care, informal peer support and meaningful work experiences.⁸

Mourning:

Jesus wept at the death of his friend and in solidarity with Mary and Martha's grief, then why would we expect our professional hospice care givers to respond differently? Yet we do, our expectation is that these professionals enter the life of each client with openness and vulnerability to care for the dying until that client dies then the expectation is to have professional boundaries and to delineate that death to a less affective space. The mourning or grieving is taken from them. The needs of the hospice care professional have been forgotten. The laws for Health Information Patient Privacy Act (HIPPA) has caused considerable issues for the hospice care professional to debrief with family or friends for fear of violating the privacy of the dying and their rights. This leaves co-workers who are burdened with their own losses and trauma. In the study done for the nursing staff at Johns Hopkins Children's Center, 113 debriefing sessions were held and analyzed. These sessions were held upon request following the death of a patient. During the three-year period, February 2002 through December 2005, 676 professionals participated. The most frequent reason for requesting a session was professional distress. The results from 184 evaluation forms found the debriefing sessions to be helpful (98.4%), informative (97.8%), and meaningful (97.8%).⁹ This study has been a catalyst to inspire more research for those working in the hospice care field.¹⁰

⁷ Ibid. 1

⁸ Ibid. 2

⁹ Keene, *ibid.* 188

¹⁰ www.nhpco.org referenced in an email response by Jon a researcher for the organization.

Interpretive:

I was attending Golden Valley Lutheran College (GVLC) in the fall of 1979 working on a degree towards missionary work. My intuition was on high alert as I was on my way back from visiting my sister, something was wrong. Back on campus, there was a note to call my brother in Oregon. Immediately a sense of trepidation set in. Calling the number, I was greeted by a voice I had not heard for quite some time. My father and brother had left the family when I was ten. Calls were rare. My brother informed me of my father's health condition. My father had fallen and hit his head causing him to be hospitalized. The doctors were not giving him much time to live. A good friend flew me to his bedside and traveled the rest of the journey with me.

A prior experience of God in my youth assured me to call upon God for strength and encouragement. It was an uncertain time and new territory a role I was unfamiliar with. It was a call to the bedside of a dying father. Physically this man did not represent the father that I recalled. Retreating, I took a step back to look at the name on the door, Alvin Kent, assured of his identify I returned to the room. The movement of his body, thrashing and moaning, made it evident that he was suffering tremendously. Nurses and Doctors explained that drugs don't help relieve pain when the liver is not working. The liver diffuses the pain medication to the rest of the body. When that organ is not working pain is a significant part of the end-of-life. The change in his breathing told me he knew of my presence. I began to abide by speaking words of comfort and peace. I allowed words of forgiveness to seep into the sacred space we were holding together. His peace was palatable as he relaxed.

God provided this time and place for my intersection of faith to be fortified by a sense of hope and truth. I understood God to be merciful and greater than anything I could anticipate for him. Praying Psalms and speaking words of forgiveness with my brother visibly relaxed my

father. I recall his last breath as he completely allowed his soul to be redeemed by the presence of holiness which I refer to as the angels entering. As he allowed his soul to release itself to redemption his countenance changed from a face of suffering and discord to a face awash in peace. There appeared to be no more suffering. A sacred veil was lifted as God revealed Himself, we sat in this liminal space with our father. We left rejoicing. The nurses were profoundly affected by the peace that we exhibited. Our rejoicing confused them. The recollection of this event creates within me a remembrance of God's revelation. This experience graced and blessed my life journey offering me hope and a reference point to understand God's merciful love. Death, through the lens of this experience, fortified my ability to abide with the dying in a sense of knowing and understanding of grace, peace and beauty. Perhaps this research is an attempt to honor the health care professionals that walked the journey with me. The disturbance of death to these nurses resides in my heart.

Soul value:

“Faith is the ground on which we stand to face life's challenges and mysteries; it is both an attitude of trust and a way of finding meaning in life as it unfolds.”¹¹ Understanding the human person as a threefold being helps one to recognize the body, mind and soul working in unity with one another. When one part of the body is neglected the other parts suffer. In the church when one person suffers the entire body suffers. American society is focused on the individual and not on the collective whole. In Felicity Kelcourse's book *Human Development*

¹¹ Kelcourse, Felicity. *Human Development and Faith: Life-Cycle Stages of Body, Mind, and Soul*. Pg. 1 and 2. Christianity and other forms of religion allow one to face difficulty in life with trust and confidence to face any fear.

and Faith: Life-Cycle Stages of Body, Mind, and Soul; she affirms that although one is an individual we are created to live in community.¹²

The description of hospice care or palliative care for end-of-life given by the World Health Organization: is an approach that improves the quality of life for the patient and that of the family who are facing life threatening illnesses. The goal is to aid the patient and family members in the early identification of pain that can be mitigated for comfort measures. This hospice or palliative care model also addresses the psychosocial and spiritual needs of the patient and the needs of the family to create a best care or practice of care with the dying.¹³ The professionals that are trying to replicate the role of the family in instances of end-of-life care are profoundly affected by countertransference responses. Countertransference is an emotional entanglement with a client, and it happens when the hospice care professional is emotionally responding to the patient in their care. Renee Katz and Therese A. Johnson share this story about countertransference that clearly depicts the trauma associated with countertransference.

“Mrs. Douglas, A 48-year-old married women, was admitted to the cardiac intensive care unit after a massive heart attack. Mrs. Douglas did not respond to maximum medical interventions and was put on a ventilator. It soon became clear that rather than helping Mrs. Douglas’s medical conditions, the ventilator appeared only to be prolonging her dying process. A decision was made with her family to withdraw Mrs. Douglas from the ventilator. Believing that Mrs. Douglas would die shortly after, her cardiologist requested assistance from a palliative physician skilled at medication for comfort during the process of ventilator withdrawal. The palliative care physician spoke with Mrs. Douglas’s husband and with their 15-year-old daughter, Hillary. Hillary, understanding what was about to transpire, requested to be with her mother during the process of withdrawing the ventilator. The Palliative care physician did not explore the meaning or the appropriateness of this request with Hillary and her father and did not consult with the palliative interdisciplinary team. Rather, believing it would be too traumatizing, she unilaterally refused the request. The ventilator was removed, while Hillary sat on the floor outside the room and wailed her grief. This helplessness and frustration were echoed by the deafening silence of the palliative team’s social workers, whose expertise was not invited nor asserted.

¹² Ibid. 2 “to counter the individualistic tendency in depth psychology, family systems theory reminds us to think in ecological, whole-system terms about the interpersonal, temporal, and environmental context in which individual lives unfold”.

¹³ Katz, Renee S; Therese A. Johnson: *When Professionals Weep: Emotional and countertransference Responses in Palliative and End-of-Life Care*. 128

Unfortunately, all this went unexamined at the time, leaving stranded five women whose emotional lives were greatly impacted and, for the moment, were all intertwined.”¹⁴

This story illustrates the magnitude of emotional response that goes unchecked in this profession. With this child sitting outside her mother’s room, wailing in grief, the healthcare professionals reacted with their own identification of what should have happened and did not. When trauma induced moments occur and are not addressed, they create a narrative of trauma. This missed opportunity to assist in the care of the dying mother or the care of the grieving daughter created an emotional response that required this team of professionals to examine what each one had responded to and to unfold the countertransference responses that each one had participated in. It is imperative for this team’s emotional, mental and spiritual health, to debrief after a traumatic death experience. Each individual professional has a narrative that is uniquely theirs and with that comes the emotional response to this trauma. Sitting down and discussing with one another or with a spiritual care provider, mental health care provider, allows a process of sharing in the trauma and unpacking those emotional responses by recognizing what specific action one is responding to.

Hospice is a community of health care professionals and volunteers who care for the dying, their families and or communities.¹⁵ The care for the dying has been a work of mercy in the church for centuries.¹⁶ Hospice care professionals are continually exposed to stressful and or traumatic experiences that are either positive or negative. Stressful events include frequent

¹⁴ *ibid.* 129,130

¹⁵ Katz, Renee; Therese A. Johnson. *When Professionals Weep: emotional and countertransference in palliative and end-of-life*. 152. The hospice movements stated mission is to neither aid nor hinder prolonging life but to offer a good death.

¹⁶ Sudek. 10. “The term “hospice” was first identified in medieval times when it referred to a place of shelter and rest for weary or ill travelers on a long journey.” In the 16th through 18th century religious orders cared for the dying.

encounters with death reminding one of one's own mortality. The reactions of the family members or caregivers, observing extreme pain and discomfort, disagreements with the treatment and care plan all create a point of intersection for emotional response and non-response.¹⁷ The lived reality of the hospice care professional intersects with their personal mind, body and soul. The continual exposure to these stresses requires a pastoral response that journeys with the professional allowing them to divest the trauma that burdens their souls. One form of care that is a part of research is debriefing. What exactly is meant by debriefing? It is a term that is used to define the coming together to process responses to situations one has experienced. In the case of hospice or end-of-life it is utilized to share sacred stories of the experience of each death and the meaning that it holds for the hospice care professional.

These hospice care professionals are part of the body of Christ and require that we compassionately serve their needs alongside the needs of those they serve. Much of the care for the hospice care professional has been relegated to the mental health professional. The soul or spiritual needs of the hospice care professional has been forgotten or left out of the continual care of the spiritual care department. Research indicates that most hospice care professionals responded that some form of debriefing is helpful and that if offered they would choose to participate.¹⁸

Who Cares?

¹⁷ Ibid. 2. Burnout is defined as a syndrome composed of emotional exhaustion, depersonalization and reduction of personal accomplishments.

¹⁸ Sudek. 28

One might ask who should be responsible for the care of the hospice care professional? In *Laborem Exercens 13*, one must not profit from the labor of another.¹⁹ The responsibility of the spiritual care department is for the healthcare professional as well as the dying. The Chaplains and Spiritual Care providers are not being called on to provide formal debriefing sessions. In the process of this research the understanding for the role of the Chaplain or Spiritual care department has not been called upon enough to provide care to the hospice team. If a critical incident happens then there is a protocol in place which generally involves the mental health or social work department.

Compassion is burdensome:

Compassion fatigue is causing many to burn out within the hospice care environment (See appendix ii for symptoms of compassion fatigue).²⁰ When the hospice care professional cannot relieve the symptoms of suffering, or the client dies suddenly the effect is more profound than when the client dies peacefully. While interviewing a social worker she stated that, “when the death is anticipated due to the age of a client it causes less trauma. However, we experienced an unusual death last year that still resides with me, she was out of the normal age range and a young victim of cancer.”²¹ It is valuable to the hospice care team to debrief and to express their reaction of how the death has affected them.

As a volunteer and intern working in hospice environments, I have witnessed these varied effects on the nurses, doctors and support staff. Compassion fatigue may have a very

¹⁹ Charles, Rodger SJ: *An Introduction to Catholic Social Teaching*. 66. “Capital was set in opposition to labor, considering labor only according to its economic purpose: the materialistic error of economism.”

²⁰ Sudek, 2. “Compassion is defined as a deep sense or quality of knowing or an awareness of the suffering of another coupled with the wish to relieve it.”

²¹ Tina Turner. Social Worker. Phone interview. 03/04/2019.

rapid onset and it can be related to a death that the nurse or support staff is exposed to. This is called countertransference. “A natural, appropriate, and inevitable response that helps professionals understand intrapersonal and interpersonal process that unfold between a person and a therapist”²². The responses in critical illness, death and dying are naturally stronger due to the unique realm of thought and practice.²³ I recall a death that caused an emotionally charged response for most of the staff. A veteran nurse who has been working in the hospice setting for over 12 years shared that she was so emotionally affected by the death of this client that she was having difficulty focusing on how to respond to the family or her fellow hospice care team. The critical incidence required a response. The entire staff and family gathered together to do a sacred sharing. This allowed staff as well as family time to process and mourn the loss of this wife, mother, and co-worker. Death surprises even the veteran hospice care professional. This professional is expected to disengage from emotions and return to the work of listening and caring for the dying and the family. As soon as death occurs the hospice care professionals are to “turn” off the emotional button.²⁴ As pastoral leaders one must assess what care is needed for the professional care giver and then proceed to care with compassion and understanding as stories unfold. Death has a profound effect on all people, let us now explore the reason why according to Terror Management Theory, a social theory based on the need for one to deny that one is dying.

Denial of Death

²² Katz, Renee; Therese A. Johnson. 3. In this case the end-of-life care professional.

²³ *ibid.* 4

²⁴ *Ibid* 3. “Studies that lead to understanding of the hospice team experience are needed in order to develop interventions that promote compassion satisfactions and provide relief and recovery for those providing care.”

“Terror Management Theory (TMT), the combination of a basic biological inclination toward self-preservation with sophisticated cognitive capacities renders us humans aware of our perpetual vulnerabilities and inevitable mortality, which gives rise to potentially paralyzing terror. Cultural worldviews and self-esteem help manage this terror by convincing us that we are special beings with souls and identities that will persist, literally and/or symbolically, long past our own physical death.”²⁵ Ernest Becker, a cultural anthropologist, wrote several books synthesizing insights from anthropology, sociology, psychology, philosophy, religion, literature and popular culture to answer a question, “What makes people act the way they do?”²⁶ The understanding that the human animal must comprehend that one day they will die and then to embrace that knowledge with the understanding that it may be a tragic or painful death creates disturbance in the fine balance of the psychological and spiritual needs of the individual.²⁷ Becker hypothesized that humans confronted the idea of death by a cultural identity. “Humans live within a shared symbolic conception that is culturally created and maintained.”²⁸ In order for one to confront the anxiety of death it is important to adapt cultural views that one is important to one’s society. These views maintain ideations of immortality if one prescribes to the life that is good enough to live on into eternity. Such as Christianity and the teachings of Christ that one is saved from sin, or separation from God, by the life, death, and resurrection of Jesus Christ. Self-esteem relies on the ability of one being able to see oneself as valuable.

²⁵ Solomon, Sheldon; Jeff Greenberg; Tom Pyszczynski. *The Worm at the Core: On the Role of Death in Life*. 127.

²⁶ *ibid.* vii-viii

²⁷ Solomon; “knowing that aversive events can and do occur creates a need for assurance that one can be spared such outcomes.” 96.

²⁸ Solomon; The understanding of the culture allows one to accept the terror of the one certainty that is constant, that all life will end. 96

Living up to the standards of the cultural world view is what allows one to perceive one's immortality. Immortality is promised by rituals and beliefs that are practiced in the culture. When one lives up to the standards and meets the requirements the soul is considered to live into eternity, an after-life or becoming one with the universe.²⁹ The sense of value to the culture creates a sense of self-worth that allows the individual to accept that they are mortal and will one day die. The process of understanding one's value in the culture is created by good actions that garner the individual an eternal soul. It is the unconscious linkage between valued behavior and safety that gives self-esteem its anxiety-buffering properties.³⁰

Using Becker's book, *The Denial of Death*, Sheldon Solomon, Jeff Greenberg, and Tom Pyszczynski defined Terror Management Theory (TMT). These psychology researchers compiled over twenty-five years of experimental social psychological research to write *The Worm at the Core: On the Role of Death in Life*. This work shares how efforts to manage existential terror affect virtually all human affairs. Concerns about mortality influence decisions from the most mundane to the most complex. The tenets of this theory are born out of one's cultural worldview and self-esteem.³¹ The cultural worldview of death in America is to fight against death at all cost. Medical professionals do everything possible to sustain life. The hospice care professional is living in a dichotomy of knowing death yet living. Faced with this dying process continually transforms that dynamic into a dualistic thought pattern that disrupts the spiritual nature of dying.

Cultural worldview is an awareness of oneself as part of a broader social context: One becomes Brazilian, Nigerian, Mexican, Italian, Lebanese, Chinese, Dutch, Mexican, Japanese, or

²⁹ *ibid.* 97

³⁰ *ibid.* 100

³¹ Solomon, Greenberg, Pyszczynski. 14. When and how does death enter the psychological picture?

American, in a wide world. Most of these social implications are well developed by the time a child is five. One is influenced by the parents or caregivers to understand the importance of one's existence. All people require self-esteem to feel good and valued and this feeling of value is essential to manage one's terror of death.³² Discovery of death begins around age three when a child comes across a dead animal or the death of beloved relative. It is not long after this discovery that children correlate others dying to the awareness that they could die too. Soon nightmares known as night terrors slip into the subconscious. The child is working out the terror of the awareness of the fragility of life.³³ As the child matures and becomes aware of the lack of control over death, the realization settles in that its death is inevitable. The knowledge of death as inevitable and irreversible creates a psychological allegiance to one's culture.³⁴ When those cultural norms are challenged or questioned what happens to the conscious thought of death? Cultural icons help keep mortal terror at bay.³⁵ The significance of the icons and the power of faith contribute to the management of the terror of death giving it order.

Living while Dying:

In order to live within the context of dying one must be able to navigate the understanding of the incarnate being and how that being is a part of the body of Christ. As a member of the body of Christ one lives in the freedom that death is a door to life. Becker's work in the 1970's helps to navigate the terror of death and bring the reality of death into order by believing in something greater than oneself.

³² *ibid.* 21.

³³ *ibid.* 24.

³⁴ *ibid.* 29.

³⁵ *ibid.* 32.

Working in the field of hospice places one in the dichotomy of life and death. Talking about the dying process with people has challenges. Most people who are broached with the subject of dying will end the conversation quickly or avoid it. Having had multiple conversations with older adults who choose not to fill out advanced health care directives has given insight as to the power that the terror of death has to human action. Human beings embrace their reality with three cognitions. One is to conceptualize causality; another is to understand future events and a third is to reflect upon our own self.³⁶ Knowing that life ends causes the terror and denial of death.

When a hospice care professional is confronted with the understanding that they are working in a field where everyone dies, they understand the dichotomy of their own existence within the tension of the work they are performing. This is an exhausting and sometimes extremely confusing tension. Those who have experienced a good death with a friend, co-worker or family member and it is a positive and loving experience may then choose to work in this field. The hope is that they will be able to replicate this experience and possibly pay-it-forward. However, over time and being exposed to a death that is particularly difficult or traumatizing to the hospice care professional causes this dichotomy to collapse into a humane reaction of the denial of death.

In the beginning of the work done by Solomon, Greenberg and Pyszczynski the *Terror Management Theory* was not widely accepted as credible. Over the next twenty-five years these professors of Sociology and Psychology validated their theory with studies to support the

³⁶ Solomon, Sheldon, Jeff Greenberg, Tom Pyszczynski; *A Terror Management Theory of Social Behavior: The Psychological Functions of Self-Esteem and Cultural Worldviews*. (95). Human beings are a part of the created species but are endowed with greater ability to understand that in the future they will die.

research of the denial of death and the terror that it caused human beings. In the book, “*The Worm at The Core: On the Role of Death in Life*”, all their findings are summarized. “Terror is the natural and generally adaptive response to the imminent threat of death.”³⁷ This feeling of terror drives our response to fight, flee, or freeze. Imagine that one must navigate this interior sense of fleeing the scene when a client is dying. On the converse one is compelled to fight with all the instruments available to keep the client living. This is known as a medical model of death rather than the peaceable and less invasive mission of hospice. Recently I experienced that very dichotomy. The man who was dying understood on one level his health was in peril but on the other level he held on tight to a scripture that he had read the day that he had surgery for his heart. In Ezekiel 36:26 “I will give you a new heart” he and his wife shared this with me the first day that I met him. Even though his health continually declined, and staff interjected with options to receive hospice he and his wife and family, held firm to the belief that he would be getting better and going home. Many days later he died in the ICU hooked up to machines and still fighting for his new heart. Hospice care professionals are confronted with this reality every time they walk through the door to assist the dying.

Cultural values:

One’s culture has a great deal to do with how one responds to death and dying. What is a culturally correct response to the care of the dying? Cultures vary in what they value and the very same attributes and behaviors in one society is completely acceptable while in another is perceived to be intolerable.³⁸ American society is changing at a rapid pace with the introduction of technology and the ability to respond to trauma quickly. With this technology is the

³⁷ Solomon, Sheldon; Jeff Greenberg; Tom pyszczynski: *The Worm at the Core: On the Role of Death in Life*. 7

³⁸ *ibid.*39

responsibility to understand and acknowledge that a person has the right to decline medical interventions when they understand that death is imminent. Medical interventions have created a scenario of longevity at any cost. This model of care creates a dynamic that often leaves the patient the victim of interventions that are not necessary or efficacious to the overall health and welfare of the patient. TMT allows one to understand that the terror of death is what drives the medical professional as well as the patient and family to keep fighting for life no matter the cost to the dying process.

When the client has been given less than six months to live and chooses not to seek treatments for a terminal illness they qualify for hospice, palliative care or various ways to seek end-of-life care that will allow for comfort measures and a non-medical intervention process. Having worked in this industry for several years now, I have been privileged to abide with many dying people. Each death is unique and chosen by the dying person.

One gentleman who was at the end stages of his life suddenly got out of bed and started doing laps around the house. He stated that he just could not be dying yet as he had an eight-million-dollar deal that he was working on. This reaction left his wife astonished and emotionally traumatized because he was so heavily invested in making money until he died. He was culturally biased by his need for doing work until he died. His self-esteem involved the financial deals that he was familiar with. She felt that his priorities had been misdirected and was concerned for his soul. The terror of death had overwhelmed him. This patient's denial of death did not bring comfort or strength but a sense of anxiety and loss. He was feeling that all his value was wrapped up in the money he earned and the deals that he made.

Self Esteem:

Self-esteem is a driving force for how one operates in the culture one is raised in and how to operate at optimal levels within that societal narrative. These actions reflect the roles and values provided by the culture.³⁹ Through experimental research, Solomon, Greenberg and Pyszczynski ascertained that there is strong evidence to indicate that self-esteem keeps the physiological arousal associated with anxiety in check. Self-esteem is felt deeply within the body it protects one from deeply rooted physical and existential fears.⁴⁰ This self-esteem allows one to see oneself as valuable within the cultural drama that one resides.⁴¹ I recall a hospice client who spent every final day making memories with his family. His cultural values were to leave a legacy related to be a tangible memory for his daughter and wife. He played music and sang until he couldn't anymore. These memories were invaluable to them after he died. The recordings have brought great comfort to the family.

While working in the hospice setting one is confronted with mortality. Often the journey is riddled with uncertainty and fear. When the fear creates anxiety and unrest for the patient it is transferred to the hospice professional. This fear or anxiety creates emotional disturbances for the team who is caring for the family and the patient. On the converse side when a dying person understands their own self-worth and enters the final stages of life the fear and anxiety are not as palpable or present. These patients offer peace to family, friends and those who are caring for them. Knowing their own mortality and what will happen in the dying process allows the client a journey that brings peace and comfort to the healthcare provider. I remember a client who was in her 90's. She smiled and offered words of comfort to the physician as well as the

³⁹ Solomon;39 "Cultures vary in what they value."

⁴⁰ *ibid.* 45 The experiments that participants engaged in helped to understand the component of self-esteem and how it allows one to anticipate death, higher self-esteem lessened the fear of death.

⁴¹ *ibid.* 97

interdisciplinary team. When asked if there was anything, we could do to assist her or make her more comfortable she would smile and say, “Oh...I can’t complain.” She was ready to die and going peacefully to a place she seemed very comfortable with. This death is an example of a positive effect on the hospice care professionals. It is in these deaths that one finds comfort in abiding and caring for the dying person.

Normative:

Sharing the stories of the dying allows the healthcare professional time to digest all that has transpired and how the interpretation of a death has personally affected one. Each person has a unique and individual story that affects the work that is done in hospice settings. The professional that has good self-esteem and has come to a place of comfort with one’s own mortality may be more apt to regulate their emotional responses to the death of clients. Since each person is individual in the response that they have it is important to give voice to the hesitations or emotional responses and care for the hospice care professional to establish a routine of care that allows one to vocalize how each death has affected or not affected the team.

Expectations of the forgotten:

The expectation to care for the dying without emotional or spiritual entanglements is causing distress for the workers in the vineyard of hospice.⁴² It is crucial that the hospice professional be cared for with generosity and insight. When we neglect the professionals in hospice, we neglect the dying.⁴³ We are causing harm to the whole body. The need for hospice has grown as baby boomers enter the end-of-life journey. More people are reaching an age where

⁴² Sudek, 68. One might hypothesize that a relationship exists between stressors and burnout and compassion fatigue.

⁴³ *ibid* 76.

end-of-life care is needed and fewer and fewer families have been opting to care for their aging relatives at the end-of-life. The use of hospice has become more prevalent in the U.S. and is gaining ground and respect from the general public as well as the global church. The chaplains or spiritual care teams are trained to assist the professionals who work in hospice. Debriefing methods as well as countless other tools are available to the Chaplains to work through the stresses that come with the secondary trauma these professional men and women experience daily. ⁴⁴

Should a professional weep?

Jesus wept at the death of Lazarus. In John 11:35 Jesus wept at the death of Lazarus, he was grieved by the death of a friend and joined in the grief with Mary and Martha the family of Lazarus. All professional hospice staff are grieved by death. The expectation of a hospice care professional is for them to “handle” their emotions and recognize symptoms of compassion fatigue and then implement self-care. Jesus taught us to weep at the loss of a loved one, why do we expect our hospice care professional to “handle” their emotions? Research uses the word “iron Maiden” to describe a nurse who has been overexposed to trauma that has not been divested by debriefing methods.

33. When Jesus saw her weeping, and the Jews who came with her also weeping, he was greatly disturbed in spirit and deeply moved. 34. He said, “Where have you laid him?” They said to him, “Lord, come and see.” 35. Jesus began to weep. 36. So the Jews said, “See how he loved him?” 37. But some of them said, “Could not he who opened the eyes of the blind man have kept this man from dying?” 38. Then Jesus, again greatly disturbed, came to the tomb. It was a cave, and a stone was lying against it. 39. Jesus said, “Take away the stone.” Martha, the sister of the dead man, said to him, “Lord, already there is a stench because he has been dead four days.” 40. Jesus said to her, “Did I not tell you that if you believed, you would see the glory of God?” 41. So,

⁴⁴ www.nhpco.org self-care for the professional and the role it plays in the care for the dying.

they took away the stone. And Jesus looked upward and said, “Father, I thank you for having heard me. (John 11: 33-41) NRSV⁴⁵

In the Oxford commentary, the NRSV translates the Greek as ‘was greatly disturbed’ implying anger. Possibly that Jesus is angry with the power of death confronting him. He could not lessen the sorrow of his friends Mary and Martha. His sorrow is real, but at the same time he envisions his fight against Satan.⁴⁶ In the Cambridge Greek commentary, the Greek translation of Jesus wept means that he was moved with indignation in the spirit. It expresses not sorrow but indignation or severity. Some say that he was angry with the human emotion that overcame him. Others say that it was at the momentary triumph of evil, as death. Others believe it was at the hypocritical and sentimental lamentations of his enemies the Jews mingling with the lamentations of Mary and Martha. Regardless of each translation Jesus has an emotional response to death. Death is viewed as the enemy of life. The hospice care professional must be allowed to weep. The emotional burden of compassion fatigue while caring for the dying transforms the soul of the hospice care professional by shutting down response and fencing off the truth of what death causes one to feel.

Jesus knew that Lazarus would rise from the dead. He still wept. The hospice professional knows that they will be seeing the death, they still weep. Just as one of the social workers said to me that they expect most deaths and they are not as affected by those, yet she acknowledged that other deaths are more painful. The loss of his friend Lazarus caused deep grief within Jesus. Mary and Martha grieved the loss of their brother, Jesus stood in solidarity with the emotional response

⁴⁵ (Division of Christian Education of the National Council of the Churches of Christ in the United States of America 1989)

⁴⁶ Barton, John, & John Muddiman. *The Oxford Bible Commentary*. Oxford: Oxford University Press. USA-OSO, 2001.

to the loss of life. The hospice care professional recognizes the suffering of the family and they stand in solidarity with this loss and grief. It is natural to respond to death with weeping. It is natural to be angry with death this is one of the stages of death according to Dr. Elisabeth Kubler-Ross who designates five recognizable stages that characterize the death process.⁴⁷ Encountering death moves one in a deep and intimate manner allowing one to understand one's own mortality. In religious imagery the inner space of awareness is called the soul, "the soul is the primordial connectedness of the human person with the Sacred, or Spirit, or God, or with whatever other words denote Ultimate Reality."⁴⁸ The hospice professional that understands the process of death as a spiritual rite of passage has a greater sense of purpose and peace with the dying process. The spiritual care department abiding with the professional in this journey allows conversation around the questions that arise with each death experience.

The ability to come together and process the death of clients in the setting of sacred space has been found to be beneficial to the professional staff and therefore to the client receiving services from the staff. When the spiritual needs of the professional are being met with answers about hard questions then that worker can see the power of God's love as they abide with the dying. One faces mortality and because of our human nature it feels unnatural to assist those who are dying to have a "good" death. There are times of great distress that happen in the process of death. Disagreements about course of action. Family members who are arguing and needing closure. The dying who need to say goodbye.

Who Helps the Helper?

⁴⁷ Kelcourse, 292 the five stages of dying are denial, anger, bargaining, depression and then acceptance.

⁴⁸ ibid. 295, The temporal and the eternal are unified by death.

One must draw on the strength of understanding eternity and allow for healing graces to disrupt the power of death. God is present in this world. This is the power of the incarnation. Ronald Rolheiser, O.M.I., is a specialist in the field of spirituality and was president of the Oblate School of Theology in San Antonio, Texas. He explains the incarnation as Christ being present to dwell among us. In the Eucharist God is real.⁴⁹ The concept of the incarnation is that God took on flesh and came to live among us for 33 years and then just disappeared back “up” to heaven.⁵⁰ Rolheiser wants the Christian to understand the incarnation to be ongoing. As members of the body of Christ we are called upon to bring healing and health.

Reconciliation and the Forgiveness of Sins:

Forgiveness in the field of hospice is immense. The dying struggle with the idea that they can seek forgiveness and can offer forgiveness. In the incarnation Rolheiser states that we have our sins forgiven by coming to the table and being in communion with one another. As the family gathers around the bedside, the experience of this act of reconciliation creates space for sacred movement. Reconciliation is part of the Incarnation. The hospice care professional experiences reconciliation with family and with the dying these experiences transfer to the professional via their own lived narrative.

Binding and Loosing:

Rolheiser goes on to say that as a member of the body of Christ we have power to bind and to loosen. When we offer forgiveness or love to those whom we care deeply for that offering is of God. Hell is only possible when one has put oneself totally out of the range of love

⁴⁹ Rolheiser, Ronald. *The Holy Longing*. New York: Crown Publishing Group, 2014. 80 “God still has physical skin and can still be physically seen, touched, and smelled, heard and tasted.”

⁵⁰ *ibid.* 76 It is a one-shot incursion by God into human history.

and forgiveness.⁵¹ God does not choose hell for anyone He can only love and bring mercy to the soul it is the movement of the soul that creates the sacred union. The doubts that are constantly nagging the hospice care professional causes disruption in their own understandings of the mercy of God. When a client is suffering in physical pain the staff can offer medication to eliminate much of that pain. When the suffering is of a spiritual nature the staff is uncomfortable with offering certitude in what is happening. More experienced staff offer what they believe to be incarnate abiding. Less experienced staff will attempt to avoid any conversation around the eternal soul. In my experience of hospice care I have had clients who have chosen to reject love and forgiveness and want to be left alone. This space is very dark and cold. This is a choice made by the dying that must remain respected. With this comes great grief for staff who believe in the mercy of God but also acknowledge that each person has the right to accept or reject God.

Anointing Each Other for Death:

When Mary anoints the feet of Jesus with costly perfume he says: “She has just anointed me for my impending death.”⁵² The bedside care of the dying is an important role and gives them a great sense of being loved. This gives the dying a sense of peace rather than bitterness at the end of their earthly journey. The incarnation has given us incredible power to look into the eyes of the dying hold their hand and anoint them with the love of God to send them into a peaceful death. This past fall I was abiding with a dying woman in the nursing home. Her family had gotten weary of the battle and wanted to rest for a while but did not want her to be left alone. I was called to come and abide with her. I asked her if I could sing songs to her and

⁵¹ ibid 89 “when one has rendered oneself incapable of being loved and forgiven in that he or she has actively rejected not so much explicit religious and moral teaching and practice as the love of sincere humanity.”

⁵²ibid 91 “because of this it will be easier to not give in to bitterness, easier to die. Knowing that I am so loved it will be easier to leave this world without anger in my heart.”

then I recalled trying to memorize psalms for a class. I asked if she would mind helping me to learn Psalm 121. I read it in Lectio Divina style, a monastic practice of scriptural reading, meditation and prayer intended to promote communion with God, and the third time that I read the 121st Psalm she sat straight up in bed looked up and took a deep breath, lay back down and died. Her countenance changed as I watched her. She no longer looked gray or pale. The look of pain and suffering that she had been exhibiting prior to this, disappeared. This was an incarnational moment. The staff commented as they came to visit her that she looked as though she were in peace. By the time family arrived she looked as if she had gotten younger. The consolation of this death stays with me and gives solace for those times when death is not as beautiful. This research has shown that the young nurse who came to “turn” her and realized that she had died may have benefitted from debriefing. She left with anxiety and uncertainty at what to do or how to react. She disclosed that this was her first experience with death since she had been working at the nursing home. She appeared to be visibly traumatized by the death.

Pastoral Response:

The care for the hospice care professional in the vineyard of the dying has been relegated to the secular establishment. This research wishes to establish a pastoral response that will provide a protocol for the chaplain or spiritual care person to care for the hospice care professional by providing debriefing sessions. The name chosen for these debriefing sessions is sharing of stories or S.O.S. This pastoral response will allow the chaplain to provide a formal setting on a regularly scheduled time to assist the hospice care professional and volunteers to share stories and debrief after the death of a client.

The hospice care professional benefits from the understanding of one’s own mortality to understand the process of dying. “A review of what happened to the patient with an emphasis on

how the healthcare team responded may at least help the student realize there was no way in which the healthcare team could have prevented the death. Later, many nursing students and nurses question why the person had to die at this time in his or her life. Active listening by the nursing faculty member or perhaps the hospital chaplain is most likely to assist the student to come to some understanding of the death.”⁵³ This is just one of the many examples that are included in research that delegates the role of debriefing to the more seasoned staff, or the mental health care team. The chaplain is consulted **sometimes** and then often only when it is considered a critical incident. Understanding dying from the perspective of eternal life, with the ideation of dying being a movement from this life to the next, creates a sacredness to the work that our hospice care professionals in this vineyard experience.

The pastoral response is a debriefing session that can be utilized by the staff at many opportune moments while caring for the dying. It is available to be led by a member of the interdisciplinary team. It can also be used by individuals to allow space for debriefing when the team cannot come together because of time or staffing constraints. A few easy examples are in the appendix and can be downloaded and copied for the use of debriefing. The acronym S.O.S. stands for sharing of sacred. In each debriefing session one will have a word to offer using the letters in the word hospice.

H stands for honor,

O stands for offering,

S stands for suffering,

⁵³ Gray, Marvin: *Palliative Care Nursing: Quality Care to the End-of-Life*. The Chaplain is just mentioned as an option for assisting the student and staff but is not given the designation as the provider.

P stands for peace,

I stand for interesting,

C stands for creativity,

E stands for energy.

The debriefing begins with prayer in the tradition of the ones who are participating. Followed by a verse in scripture, a poem, a meditation, sacred text or reading. Then a short one- or two-line reflection on the reading. This is followed by using the acronym of hospice to reflect on the one who died. A moment of sacred silence is observed. Following the silence is an offering of petitions. Once all have participated the leader will close with a prayer, quote, poem or Amen. Tools to follow up with self-care should be available to the hospice care professional. The observance of debriefing is just one response to the trauma of caring for the dying. When the pastoral response is implemented as a part of the work that these professionals do, it will be considered an integral part of the caring process and bring benefit to the professional as well as to those they are caring for. When a part of the body suffers and is healed the rest of the body benefits as well.

Summary:

Emotional response to death is normative and most interdisciplinary teams in research surveys have indicated that they do benefit from debriefing, talking about their emotional and spiritual response to a death, and therefore provision for debriefing has a causative

effect on the ability of hospice care professionals to optimally care for the dying.⁵⁴ Younger and less experienced nurses are more susceptible to this work related trauma. Without proper debriefing, to assist them with this response, they will often quit hospice and find work in a less trauma centered environment.⁵⁵ For the benefit of the staff and their own self-regard debriefing allows sacred stories to be shared and vocalized with honor. Weeping and emotional response to death is normative. Jesus gives us permission to weep by setting the example. Those who are in the vineyard of end-of-life care are vulnerable to the countertransference of pain and suffering from one's narrative and lived experience. The incarnation within the hospice care professional allows them to reside at the bedside with openness to the power of God in the moment of death. As the hospice care professional is exposed to beautiful deaths and the process of dying as good, they are transformed and more able to optimally care for the dying client. When the spiritual care department offers debriefing sessions and allows sacred space for the sharing of stories the hospice care professional is only one person that benefits, it is the entire body of Christ that benefits especially the dying who receive more grace filled optimal care.

The limitations of this research suggest that a more research in the development of debriefing sessions would profit the hospice care professional. It is the understanding of this researcher that those efforts are under way and the utilization of debriefing in a formalized setting is beginning to take shape and profit the hospice patient as well as those working in this field of caring. It is the hope of this researcher that whomever reads this work will take into account that all human life at every stage has great value and the ones working at the end-of-life are of great value to our society, let us care well for them.

⁵⁴ Bickham, Melanie Ann. *Distress in Nurses Following Patient Death: A Local Response to the Need for Debriefing*. Thesis for Master of Arts in Nursing, Bozeman: Montana State University, 2009.

⁵⁵ Keene, 188

Appendix i.

Professional Quality of Life Scale (ProQOL)

Compassion Satisfaction and Compassion Fatigue (ProQOL) Version 5 (2009)

When you *[help]* people you have direct contact with their lives. As you may have found, your compassion for those you *[help]* can affect you in positive and negative ways. Below are some-questions about your experiences, both positive and negative, as a *[helper]*. Consider each of the following questions about you and your current work situation. Select the number that honestly reflects how frequently you experienced these things in the last 30 days.

	1=Never	2=Rarely	3=Sometimes	4=Often	5=Very Often
1.	I am Happy.				
2.	I get satisfaction from being able to <i>[help]</i> people.				
3.	I feel connected to others.				
4.	I jump or am startled by unexpected sounds.				
5.	I feel invigorated after working with those I <i>[help]</i> .				
6.	I find it difficult to separate my personal life from my life as a <i>[helper]</i> .				
7.	I am not as productive at work because I am losing sleep over traumatic experiences of a person I <i>[help]</i> .				
8.	I think that I might have been affected by the traumatic stress of those I <i>[help]</i> .				
9.	I feel trapped by my job as a <i>[helper]</i> .				
10.	Because of my <i>[helping]</i> , I have felt "on edge" about various things.				
11.	I like my work as a <i>[helper]</i> .				
12.	I feel depressed because of the traumatic experiences of the people I <i>[help]</i> .				
13.	I feel as though I am experiencing the trauma of someone I have <i>[helped]</i> .				
14.	I have beliefs that sustain me.				
15.	I am pleased with how I can keep up with <i>[helping]</i> techniques and protocols.				
16.	I am the person I always wanted to be.				
17.	My work makes me feel satisfied.				
18.	I feel worn out because of my work as a <i>[helper]</i> .				
19.	I have happy thoughts and feelings about those I <i>[help]</i> and how I could help them.				
20.	I feel overwhelmed because my case [work] load seems endless.				
21.	I believe I can make a difference through my work.				
22.	I avoid certain activities or situations because they remind me of frightening experiences of the people I <i>[help]</i> .				
23.	I am proud of what I can do to <i>[help]</i> .				
24.	As a result of my <i>[helping]</i> , I have intrusive, frightening thoughts.				
25.	I feel "bogged down" by the system.				
26.	I have thoughts that I am a "success" as a <i>[helper]</i> .				

27. I can't recall important parts of my work with trauma victims.
28. I am a very caring person.
29. I am happy that I chose to do this work.

© B. Hudnall Stamm, 2009. *Professional Quality of Life: Compassion Satisfaction and Fatigue Version 5 (ProQOL)*.
/www.isu.edu/~bhstamm or www.proqol.org. This test may be freely copied if (a) author is credited, (b) no changes are made
and it is not sold.

Appendix ii.

Some common compassion fatigue symptoms include, but are not limited to:

- Fearfulness—Do you live in fearfulness of accidents taking place that you witnessed during work? For example, do you find yourself nervous to get in your car after tending to a car accident victim?
- Reliving moments—Do you find yourself constantly reliving moments that happened throughout your day, perhaps scenes of a patient passing away or possible alternative care routes that could have been taken?
- Loss of appetite—Do you find yourself skipping meals or not feeling hungry when you do pause to eat? Because nurses work long, demanding shifts, breaks are often skipped in favor of being there for the patient 24/7. As schedule demands grow and stress builds, it's easy to skip meals. Weight loss often follows closely behind.
- Missed work—Are you missing work? Nurses who struggle with compassion fatigue often miss work, particularly when the demands of the job grow increasingly overwhelming.
- Headaches or other illnesses—Do you find yourself encountering frequent headaches? Constant preoccupation with work can lead to intense, increased stress that often manifests itself as headaches. Sometimes other illnesses also make an appearance, often capitalized upon by lack of sleep and weight loss.
- Difficulty sleeping—When you finally get to bed, do you have trouble falling asleep or do you experience bad dreams that relive traumatic events witnessed at work?
- Loss of empathy—Do you find that you lack empathy or compassion as you interact with your patients? As compassion fatigue grows, nurses often numb themselves to the trauma they witness as a last-resort coping mechanism simply just to get through the day. This can be accompanied by sudden and drastic mood changes and increased irritability.

<http://blog.cuw.edu/compassion-fatigue-symptoms-are-you-at-risk/>

Appendix iii

Pastoral Response: Link to brochure. Copy in Word provided for reference only.

https://livecsbsju-my.sharepoint.com/personal/cfriebohl001_csbsju_edu/Documents/SOS.docx



S.O.S.

Sharing of Sacred

In memory of Virgil Hanson

Hospice Team

Dr. Amy
Charles, RN
Gladys, CNA
Polly, BCC

St. Albert the Great hospice

Great Falls
Montana



S.O.S.

Wednesday

12:30 pm

Spiritual care department



Creator

Opening Prayer: We join our hearts and minds and souls together to honor

(name).

Scripture: Jesus wept. Jn. 11:35

Poem:

Meditation:

(reading from other religious affiliation)

Reflection:

“ as Jesus wept for Lazarus we weep for (name).”

Share of Sacred how (name) represented: Honor

Offering

Suffering

Peace

Interesting

Creativity

Energy

We take this time to speak words of comfort to one another as we honor (name).



Petitions:

Creator:

Bring peace ••• for (name)family
We Pray ••• Here our prayer

Bless the hospice care team •• help our
grief

We Pray ••• Here our prayer

For any words you wish to share...
(anyone shares)

We Pray ••• Here our prayer

A moment of silence ••• to
honor(name)

We Pray ••• Here our prayer

Ending Prayer:

In thanksgiving for all that is and ever
will be
Amen

Appendix iv:

Interview Questions:

1. What is your position with the hospice organization?
2. How long have you worked in hospice?
3. Have you participated in sessions to debrief the loss of a client?
4. Are you aware of the provisions for debriefing in your organization?
5. Do you believe that debriefing would be valuable to your organization? Why?
6. What would you like to see happen for debriefing and how often?
7. Who do you understand to be the leadership for debriefing in your organization?
8. Do you have a spiritual care team or department?
9. Demographics:

Male _____ Female _____ prefer not to answer _____ Other _____

White, non-Hispanic _____

Black _____

Latino _____

Native _____

Other _____

Prefer not to answer _____

10. Do you understand compassion fatigue or compassion satisfaction and how to analyze it?

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Online Resources:

<https://www.nhpco.org>

<https://www.americanhospice.org>