

Spring 2018

“We Make Death Look Pretty”: A qualitative study analyzing reported effects of compassion fatigue on hospice nurse-patient communication

Katherine Harville

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“We Make Death Look Pretty”: A Qualitative Study Analyzing Reported Effects of
Compassion Fatigue on Hospice Nurse-Patient Communication

Katherine Harville

A thesis submitted to the Graduate Faculty of

JAMES MADISON UNIVERSITY

In

Partial Fulfillment of the Requirements

for the degree of

Master of Arts

School of Communication Studies

May 2018

FACULTY COMMITTEE:

Committee Chair: Sharlene Richards, Ph.D.

Committee Members/ Readers:

Melissa Aleman, Ph.D.

Jennifer PeeksMease, Ph.D.

Dedication

This thesis is dedicated to my Mimmy, my grandmother who passed away two and a half years ago due to lung cancer. In life, she served as one of my greatest inspirations; in death, she continues to do so. “I’ll love you forever, I’ll like you for always.”

Acknowledgements

I would like to thank the tireless efforts of my thesis committee, Dr. Sharlene Richards, Dr. Melissa Aleman, and Dr. Jennifer Peeksmease. Their constant support, patience, and guidance has been integral to not only the completion of this thesis, but also to the maintenance of my sanity throughout this process. I would also like to thank my mentor, Dr. Sharlene Richards, independently. Dr. Richards has not only helped me throughout the process of writing my thesis, she has also served as a phenomenal help throughout the process of PhD applications and choosing PhD programs. I am so excited to attend the University of Kentucky in the fall, and there is no doubt in my mind regarding the crucial role Dr. Richards has played in helping me achieve this accomplishment. From the bottom of my heart, thank you.

Furthermore, I would like to thank my friends and family for their unconditional love and support; there were times during this process when I was missing in action, grumpy, stressed, and frustrated and, through it all, they provided me encouragement. I want to, specifically, thank my parents, Ann and Randy Harville, for all of their patience and understanding. I love you and thank you.

Finally, I want to thank my research participants without whom this project would not be possible. Thank you for your willingness to share your experiences with me.

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Abstract

Rationale: Compassion fatigue is present in multiple nursing fields, but hospice poses a significant threat to nurses working within that specific environment. This is due to their consistent proximity with patient suffering, death and dying, and constant communication with patients regarding their death. The hospice nurse-patient relationship requires a deeper connection between nurse and patient which often results in consistent emotional labor for hospice nurses, further amplifying the threat of compassion fatigue. While the effects of compassion fatigue can manifest in many forms, it is typically characterized by a nurses' decline in job satisfaction, which they do not tend to speak openly about. While research has been conducted concerning the effects compassion fatigue can have on the quality of care received by the patient, there has been very little research conducted analyzing the relationship between hospice nurse-patient communication and compassion fatigue.

RQ1: What do hospice nurses report as the consequences of compassion fatigue for themselves, their colleagues, and their patients?

RQ2: How do hospice nurses think compassion fatigue influences the way they communicate with their patients?

Methodology: In order to understand the research questions under investigation, hospice nurses were interviewed using a semi-structured interview guide. Data was analyzed using the thematic consistent comparative method to identify common themes and trends in the data.

Findings: Participants discussed the multiple roles in which they felt responsible engaging, unique challenges associated with hospice work, and effects of stress and fatigue

CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

The purpose of this study is to increase understanding of how compassion fatigue affects hospice nurse communication. Compassion fatigue is defined as, “state of tension and preoccupation with the cumulative impact of caring rather than on the needs of the patient in front of you” (Figley, 1983, pg. 10). Due to the constant exposure to death and grief, as well as the frequency with which hospice nurses must break bad or unfavorable news to patients and family members, the hospice environment does not facilitate an emotionally healthy environment for workers (Ingbretsen & Sagbakken, 2016). Melvin (2012) found each of its participants had experienced some form of compassion fatigue at one point during their career as a hospice nurse. Symptoms of compassion fatigue such as depression, apathy, and difficulty sleeping result in a noticeable decline in the quality of life for nurses as well as a decline in quality of care received by hospice patients (Jackson, 2004; Keidel, 2002).

Literature Review

Hospice Nursing

A hospice nurse’s day-to-day is filled not only with the average nurse’s duties, but they are also surrounded by patients nearing the end of their life, as well as families struggling to say goodbye to their loved one. Oftentimes, hospice nurses will personally identify with their patients’ situation and sometimes pain, therefore taking on the patients’ burden (Ingebretsen & Sagbakken, 2016). In such situations, it is not clear what role the nurses should play regarding patient psychosocial support; trying to find the balance of successfully fulfilling their responsibilities, paired with the challenge of constantly monitoring one’s emotions begins to wear down nurses’ abilities to do their

jobs in most effective way. Overall, hospice environments are consistently found to have significantly high levels of stress among staff members (Whitebird, Asche, Thompson, Rossom, & Heinrich, 2013). The main source of stress for hospice nurses does, indeed (and to no surprise) come from their constant interaction with death and dying; the constant construction and deconstruction of attachments with patients serves as a significant source of stress for hospice nurses (Hawkins, Howard, & Oyebode, 2007). However, it is important to point out the already heightened level of stress within hospice institutions themselves; therefore, anything that would commonly cause stress in the work place does so on a greater level within hospice environments. This stress is further magnified by the uncertainty of the level to which hospice nurses are supposed to provide psychosocial support (Wittenberg-Lyles, Washington, Demiris, Oliver, & Shaunfield, 2014).

Hospice nurses can be used as a reference for grief communication due to the prevalence with which they deal with patient distress (Clayton, Reblin, Carlisle, & Ellington, 2014). The current communication models that provide frameworks for the way in which hospice nurses communicate with patients mainly provide insight into how these individuals communicate bad news, or comfort to their patients in distress. Specifically, the COMFORT model is one of the only models that is designed solely for hospice nurse-patient interactions. Essentially, COMFORT is an acronym for, “communication, orientation, mindfulness, family, ongoing, reiterative messages, and team” (Villagran, Goldsmith, Wittenberg-Lyles, & Baldwin, pg. 225, 2010). This model originated as a response to the tendency of hospice staff who, under immense emotional labor, began to view patients as objects suffering from medical problems rather than

people who are dying and in pain; the model lays out each component as a key competency for nurses to master and serves to ensure their patients are receiving the best care possible. Communication emphasizes the importance of nurses being proficient in nurse-patient communication; in non-bad news situations, nurses typically do not engage in upsetting topics and try to make the interaction as brief and succinct as possible. However, when delivering bad news, it is important for hospice nurses to engage in open communication to provide plenty of opportunities for patients to ask questions and have all the information they need (Villagran et al, 2010). This allows patients to feel they are in control of their situation which results in the maintenance of their quality of life; although there will be time where the patients are not in control and require significant help from nurses, it is important for their quality life that some semblance of autonomy is maintained (Johnston & Smith, 2006). Orientation is associated with the way in which hospice nurses familiarize patients with what they should expect regarding the bad news they just received. This means making sure the information is expressed using language that is most accessible to the patient, while still providing some positive information. In doing so, the nurse ensures the patient is aware of the process they are about to endure without being immensely discouraged. This is where nurses begin to create and perpetuate the feeling of what Johnston and Smith call “hospice as family” (pg. 706). The idea behind the concept is to ensure patients feel relaxed and safe in the hospice environment; by adequately orienting the patient to their situation, the patient can feel confident in their care. Mindfulness serves as a compliment to orientation; it refers to the importance of developing a genuine connection with patients to help them in comprehending their situation. Family indicates the important role the patient’s family

members play in the care of the patient; this can be in either a verbal or nonverbal capacity. Ongoing refers to the need for nurses to be engaging in ongoing dialogue with patients about the specifics of their care to prevent feelings of desertion after the bad news has been broken. This helps establish a continuous connection between the patient and the nurse which is crucial to the quality of the patient's hospice experience (Johnston & Smith, 2006). Reiterative is the importance of framing the process in a way where the meaning remains the same, but it may be phrased in a different way to help patients and their families continue to form a deeper understanding of both their diagnosis as well as their plan of care (Villagran et al, 2010). Finally, team refers to the multiple health care professionals with whom the patient will be working; team meetings with the patient are encouraged and are a good way of ensuring hospice patients feel their needs are being met. While meeting the patient's needs encompasses a myriad of things from psychosocial support to pain management, meeting on a regular basis to "check in" with the patient is important to ensuring those needs are covered (Johnston & Smith, 2006).

Additionally, the multiple relational tensions faced by hospice nurses is crucial to acknowledge due to the role personal relationships play in hospice nurse stress. As previously stated, the dialectical tensions faced by hospice nurses are, "authoritative-nonauthoritative dialectic, revelation-concealment dialectic...independence-collaboration dialectic, and quality of care-business of care dialectic" (Gilstrap & White, pg. 528-529, 2015). The first two tensions are associated specifically with patients; therefore, those are the two tensions on which the focus will remain. Essentially, authoritative-nonauthoritative dialectic is correlated with hospice nurses being viewed as, "authorities regarding the death and dying process" (Gilstrap & White, pg. 528, 2015). This

ultimately means hospice nurses are mostly looked to as the ultimate reference point in matters where there is much uncertainty specifically concerning patient comfort, care, and amount of time left. However, there are situations when hospice nurses must make decisions between what the patient wants and what will make the patient most comfortable. This is where the tension becomes apparent; there comes a point where hospice nurses may decide to allow a patient to make decisions on their comfort care plan even if it goes against the hospice nurse's authority. This can often result in the patient being in pain, but receiving the care they want, not the care suggested for them.

Additionally, the revelation—concealment dialectic appears in situations where hospice nurses want to be open and honest with patients' families, but are hesitant to do so with those families struggling to deal with the reality of their loved one's situation. The tension arises in situations where families do not want the loved one to know they are on hospice care, or where families do not want to focus on the mortality of the loved one. Therefore, nurses must decide on whether they honor the family's wishes, or if they remain as open as possible with their patients. Due to the amount of time hospice nurses spend communicating information, it is important the nurse develops a kind of partnership with the patient's family (Ellington, Reblin, Clayton, Berry, & Mooney, 2012). This tension can cause challenges to that collaboration; therefore, hospice nurses must work towards better communication as a means of resolving the tensions.

Additionally, there is the nonverbal aspect of communication among hospice nurses and patients. Hospice nurses must be careful not to place all of care quality in verbal communication, but also nonverbal; there are times when all a patient requires is a reassuring presence to feel safe and comfortable (Foster, 2012). The nonverbal

component of the hospice nurse-patient relationship is arguably just as, if not more, important than the verbal component. This is due to the existential nature surrounding most of the conversations in which hospice nurses must engage. Therefore, silence, while difficult to master, can sometimes be one of the most crucial components of nurse-patient communication; especially in the hospice environment (Strang, Henoeh, Danielson, Browall, & Melin-Johansson, 2014).

When nurses become overwhelmed by their stressful environment, they are more likely to develop coping mechanisms to aid them in handling the responsibilities of their job in a defensive manner. Nurses commonly form patterns of communicating with patients; these often fall into the categories of dealing, ducking, diverting, and deferring (Hill, Evans, & Forbat, 2015). Dealing occurs when a nurse directly addresses a need that was either directly expressed, or a need that had been expressed before. Ducking occurs when a nurse simply does not attempt to address a need expressed by a patient, diverting is when a nurse addresses either only a part of a patient's need, or simply addresses a different need than the one expressed and deferring refers to instances where nurses put off addressing the patient's needs (Hill, Evans, & Forbat, 2015). When symptoms of compassion fatigue begin to surface, hospice nurses are more likely to engage in the ducking category of handling patient needs due to the negative and overwhelming effects compassion fatigue can have.

Similar to compassionate communication, it is imperative hospice nurses incorporate a few components within these interactions presence, touch, and listening (Olthuis, Dekkers, Leget, & Vogelaar, 2006). Listening is a way of connecting with the patient; knowing the nurse is there to listen to their thoughts and concerns helps to

provide a connection between nurse and patient and touch furthers that connection.

Presence refers back to the importance of being with a patient emotionally, it is crucial for the patient to feel the support of the hospice nurse, not just hear it (Foster, 2012).

While the caring relationship is crucial to quality care, compassion fatigue can compromise this relationship and have a potential negative effect on hospice nurses' quality of work and, consequently, a patient's quality of life. Considering the lack of research regarding the connection between compassion fatigue and its effects on hospice nurse-patient communication, further research is needed to better understand the connection.

Death and Dying

Consistently engaging with one who is nearing the end of life can be an immensely stressful experience. However, hospice nurses are surrounded by multiple dying patients each day; while this certainly heightens the stress present in their working environment, hospice nurses are unique in their ability to willingly deal with death on a regular basis (Wittenberg-Lyles, 2006). The readiness of these individuals to be surrounded by death could be due, in part, to the bases of the profession. The work of palliative professionals is based in the ideas that death is a natural part of life, death should be hurried or deferred but relief from pain must be provided, patients must be encouraged to remain as active (whether it be physically or mentally) as possible until death arrives, and providing a support system to the family of the patient through both the duration of care, as well as through the early bereavement periods (Mackay & Sparling, 2000). These premises are often perceived to be in conflict with the typical goal of other healthcare professions which is to heal, or prolong life (Omilion-Hodges & Swords,

2017). Where other medical providers see failure hospice providers find their identity. As a result, Omilion-Hodges and Sword (2017) present the dialectical tensions that stem from this dissonance. The first is the living—dying dialectic, this dialectic is rooted in the aforementioned difference between hospice care and other medical care. While other medical professions actively work against death and dying, those working within hospice care lessen that focus and, instead, prioritize comfort. The other dialectic presented is the practicing—advocating dialectic; this dialectic focuses on the challenge of both caring for hospice patients, while also advocating for the specific field of work (Omilion-Hodges & Sword, 2017). The tensions experienced between hospice workers and the rest of the medical community can be traced back to death and dying. Hospice nurses serve a unique purpose in the multiple roles they play in order to adequately care for their patients. They are not only responsible for ensuring the comfort of their patients, they also provide care to patients' families by serving as a pseudo bereavement counselor, a navigator of family conflicts, and an end-of-life guide (Vedel, Ghadi, Lapointe, Routelos, Aegerter, & Guirimand, 2014). Hospice is meant to make the end-of-life process as comfortable as possible, and hospice workers put value in providing the “good” death (Foster, 2012).

The concept of a good death can mean different things to different people; however, common themes present in a good death are comfort, peace, support, and acceptance. Whereas, a bad death is often characterized as a death wrought with regret, resistance, and lack of support (Low & Payne, 1996). The idea of a good death is one that is viewed as immensely valuable within hospice care, and hospice workers are meant to almost collaborate with their patients in order to orchestrate a good death. However, the tension associated with what role the hospice provider should play works to further

complicate the already convoluted nature of end-of-life care. Within hospice, there are two primary roles hospice workers can play; the role of the follower and the role of the leader. When engaging in the role of the follower, the patient and family are seen as the experts on care and the hospice worker is meant to follow their lead because they know what is best for the patient. When playing the leader role, the hospice worker is employing their own expertise regarding the realm of death and dying (Considine & Miller, 2010). Therefore, finding the balance between playing the two roles is crucial in helping to foster a good death. Hospice workers view the providing of good deaths as a responsibility of their job; therefore, when a bad death occurs, hospice workers often feel a sense of frustration and guilt due to the belief that they have not done their job well (Semino, Demjén, & Koller, 2014).

Contrasting with a good death, a bad death occurs when the patient is experiencing pain, emotional distress, or any unresolved symptoms (Semin, Demjén, & Koller, 2014; Costello, 2005). While hospice nurses often do not have much control regarding the pace at which their patient is dying; pain management and symptom control is one the few things over which they do have control. Therefore, when this control is lost or perceived as taken away, a bad death is often cited and hospice nurses feel as if their responsibilities were not met. However, the narrative and mindset centered around good and bad deaths focuses almost solely on the wishes and actions of the providers of the care, rather than the wishes of the patient (Paynem Langley-Evans, & Hiller, (1996). In doing so, the importance placed on the quality of death is inherently strips patients of any remaining power they may have; while confidence in their ability to care for patients is

crucial, hospice and health care as an industry should not place such strict parameters determining the best way patients should die (Hart, Sainsbury, Short, 1998).

Emotional Labor

Emotional labor can be defined as the requirement to either quell or express emotion to adhere to the appearance required for one's profession (Hochschild, 1983). It is important to note; however, emotional labor does not consist of feigned emotion; instead, it is a process of monitoring one's emotions and deciding if exhibiting certain emotions meets the standards of the organization (Wharton, 1999). Hospice nurses face a unique challenge regarding emotional labor due to the requirement of social support, which requires the expression of emotions that support and understand the situations experienced by both patients and patients' families. This, paired with the requirement to remain professional, results in the challenge of finding a balance between the level of emotional work in which to engage, and the level of emotional labor that must be exercised.

Unlike other medical situations, hospice institutions present an interesting challenge to those working with patients regarding how responsible those individuals are for patient social support. This is not a question of bedside manner necessarily, but a question of the level of consolation for which hospice nurses are responsible. To patients, a nurse who is emotionally sensitive is one who is aware of and responding to needs both emotional as well as physical (Sayers & De Vries, 2008). Consequently, hospice nursing can be classified as what Miller, Considine, & Garner (2007) refer to as emotional work, or lines of work where emotion is considered central to the relationship held with clients (Miller, Considine, & Garner, 2007). With hospice care, there is a whole other area of

patients' needs that must be taken into consideration (Szulecki, 2017). This contributes to the already demanding responsibilities of being a hospice nurse; it is not enough a hospice nurse is present and attending to physical needs, they must also be present and attending to emotional needs of the patients. It is this increased importance in being there physically and mentally for patients that results in the exacerbation of challenges to nurses' emotional well-being (Wharton, 1999).

The immense levels of stress combined with the ambiguous requirements surrounding a hospice nurses' role in providing social support creates an environment wherein hospice nurses are forced to monitor their own emotional responses to their patients in order to remain professional. While emotional labor is present in most medical professions to some extent, hospice care requires such consistent emotional labor in order to adequately care for and comfort patients, therefore exacerbating the level of emotional labor required from hospice nurses (Roche-Fahy & Dowling, 2009). Duffy refers to the responsibility of a hospice nurse as "[doing] everything to make sure the person leaves this life without pain or fear" (Duffy, 2016, pg. 1). To attempt to remove emotion from this process is to remove the humanity; hospice nurses are discouraged from having an off day or, in other words, a day when they are human (Payne, 2001). Engaging in such consistent emotional labor can easily result in shows of emotion that are not sincere but, instead, fulfill a professional requirement (Tracy, 2000). This is especially harmful when engaging in emotional work; replacing genuine emotion with falsified emotion dramatically affects the nurse-patient relationship in a negative way and therefore not only causes a dissonance among nurses, but also between patients and their caretakers (Hullett, McMillan, & Rogan, 2000).

Furthermore, compassionate communication is crucial to ensuring nurses as well as other hospice staff are providing a supportive environment; this entails a process of noticing when an individual is in need of compassionate communication, connecting and engaging in the compassionate communication, and then responding, or actively engaging in compassionate behavior (Miller, 2007). While the importance of this pattern of communication is apparent, when nurses are encouraged to go through this process and be “on” all the time while consistently dealing with the reality of losing patients, this can become exhausting. This exhaustion can, therefore, result in a lack of compassion in communication as well as inflame underlying symptoms of compassion fatigue, such as depression, anxiety, or difficulty sleeping (Melvin, 2001). The emotional exhaustion, paired with the aggravation of these symptoms further affects hospice nurses’ quality of work and life and enhances the chances of nurses’ disassociation and dissatisfaction with their profession, thereby heightening the threat of compassion fatigue (Carter, Dyer, & Mikan, 2013; Tracy, 2005).

Compassion Fatigue

The healthcare field, overall, is one fraught with the potential for compassion fatigue; consistent interactions with patients paired with consistent vulnerability to high levels of stress make for countless opportunities for compassion fatigue to take hold (Mason, Lesloe, Clark, Lyons, Walke, Butler, & Griffin, 2014).

As previously explained, compassion fatigue occurs when individuals become overwhelmed by the impact associated with caring and can have drastic effects on work engagement, satisfaction, and provider well-being. (Alekan, Linton, & Davies, 2008; Figley, 1995). Multiple studies have been conducted regarding the effects of compassion

fatigue in multiple areas of healthcare and, regardless of the specific category of nurses being examined, as symptoms of compassion fatigue increased, nurses' concern for patients decreased. However, nursing fields that are most at risk to suffer from compassion fatigue tend to be those in which losing a patient is not a rare occurrence. These are fields such as "emergency, oncology, critical care, progressive care,...and outpatient nurses working in home health settings" (Sorenson, Bolick, Wright, & Hamilton, pg. 459, 2016). The aforementioned environments are consistently made up of the three biggest stressors of compassion fatigue, witnessing the suffering of a patient, losing a patient to death, and conversing with patients about death and dying. Therefore, it comes as no surprise these nurses often feel overwhelmed and underprepared to deal with death and dying on a day-to-day basis. This is, in part, due to the lack of training received by nurses during their education; nurse do not receive formal training regarding how to go about working with dying patients and the emotional turmoil that can accompany it. Furthermore, nurses do not receive training regarding how to best communicate with patients and their families in death and dying situations which, in turn, exacerbates the stress nurses already experience (Peterson, Johnson, Scherr, & Halvorsen, 2017).

While compassion fatigue can have a serious effect on those it targets, it is not easy to identify in its early stages; nurses must have an elevated awareness to the symptoms of compassion fatigue and, even then, it is still difficult for them to identify what they are experiencing until the symptoms are prevalent in their job performance and personal life (Joinson, 1992). Compassion fatigue is responsive to interventions once it is identified; therefore, learning to be consistently aware of their own stress levels and

mental health can be immensely beneficial to nurses in all fields. Once it is identified the nurse is dealing with symptoms of compassion, or even extreme stress, nurses can seek out someone who can help them to navigate their feelings and identify helpful coping strategies to ensure their symptoms are managed (Lombaardo & Eyre, 2011).

One way nurses in emotionally stressful fields develop personal evaluation skills is through the formation of a compassion identity; this serves as a centering tool that helps nurses to cushion themselves from emotional backlash. Essentially, a compassion identity is formed in order to allow nurses to continue to care for patients in a compassionate manner, while engaging in constant self-assessment to ensure they are taking care of themselves as well. In other words, it is “one’s internal global positioning system” (pg. 448). While external support in the form of mentors or friends are critical in coping with symptoms of compassion fatigue, the resources of one’s own internal coping abilities are just as crucial. Therefore, in addition to a compassion identity, nurses must be constantly working towards augmenting their competency regarding their patients’ needs. This simply means nurses must think deeper about whether a patient needs more pharmaceutical assistance, or interpersonal assistance. A compassion identity helps to augment that competency and, once developed, the increased competency and compassion identity enter a cycle of building on one another to both protect nurses from common stressors that cause compassion fatigue as well as increase the quality of care provided to patients. (Corso, 2012).

Compassion Fatigue and Hospice Nurses

From the beginning of their careers, hospice nurses are faced with multiple emotional stressors that, over time, cumulate to immense stress, mental health disparities

and, therefore compassion fatigue. Thus, it is not uncommon for compassion fatigue to become commonplace within hospice care settings (Melvin, 2012). When analyzing the effect stressors and social support burden can have on hospice nurses, it is clear when compassion fatigue takes hold, communication challenges take on a new level of difficulty and complexity (Hill et al, 2015). Similar to other health professionals, hospice nurses put a significant amount of emotional stock into their patients; however, there are certain components of hospice nurses that differentiate them significantly from their non-hospice counterparts. Specifically, compared to health care workers in traditional environments, hospice nurses are more likely to dwell on patient issues. Whereas those within more common health care environments deeply value time and are eager to settle issues and move on to the next matter. Additionally, hospice nurses tend to be more strong-willed and dominant compared to their non-hospice colleagues (Amenta, 1984). However, while hospice nurses tend to have these traits to help them in navigating the difficult terrain that is their job, this does not prevent hospice nurses from placing a critical amount of emotional capital within their patients. This can further the threat to hospice nurses' mental health, therefore enhancing the possibility of compassion fatigue (Whitebird et al, 2013). Consequently, a review of the data surrounding depression among hospice nurses found twenty-six to fifty-seven percent of nurses surveyed fell at the baseline measure of depression or higher (Parker Oliver, Albright, Washington, Wittenberg-Lyles, Gage, Mooney, & Demiris, 2013). This statistic illustrates the risk hospice nurses must face when attempting to find an emotional balance regarding their relationships with patients.

In addition to the emotional labor hospice nurses must engage in to remain professional in their day-to-day interactions, hospice nurses must also work to ensure the comfort of their patients and, therefore, are expected to keep track of not only patients' pain management needs, but also with what frequency the patient in question is required to receive a new dose (Wittenberg-Lyles, Demiris, Oliver, & Burt, 2011). This pressure of keeping up with multiple patients' pain management schedules, the prevalence of emotional labor, along with nurses' other responsibilities, can easily manifest itself in the form of anxiety; therefore, further enhancing the nurse's potential of experiencing compassion fatigue (Melvin, 2012).

To prevent the troubling nature of the job with which hospice nurses are faced, it is crucial for hospice nurses to develop a consistent self-care routine; these self-care activities can, and should, fall into multiple categories including "psychological care, physical care, emotional care, spiritual care, and workplace self-care (Alkema et al, 2008). In order to be most effective, however, it is important hospice nurses engage in multiple activities to manage symptoms of compassion fatigue. An effective self-care routine takes time to develop; therefore, hospice nurses who have been in the industry longer are more likely to have the most effective self-care regimens. These regimens tend to meet the recommendation of engaging in multiple categories of self-care activities, while also finding a healthy balance between their work life and personal life. In doing so, hospice nurses create a better quality of life, are less susceptible to compassion fatigue, are able to better cope with the mental demands of their daily routines and are over all more satisfied with their work (Alkema, et al, 2008). In addition to productive self-care routines, it is crucial for hospice nurses to talk about their experiences; however,

those struggling with the realities of their job are not always willing to seek support from other staff members to discuss their experience. Some research has been done to provide some way to attempt to identify those who may be suffering, but do not feel able to speak about their struggle (Whitebird et al, 2013).

Attachment theory offers four types of attachment styles secure, preoccupied, fearful and dismissing. Secure individuals are view themselves as deserving of support and are open to seeking the support they require. Preoccupied individuals are constantly working towards gaining acceptance and support and, therefore, become very dependent. Fearful and dismissive individuals are resistant to seeking support in stressful situations and do not view others as a reserve of support (Hawkins, Howard, & Oyebode, 2007). Those who are preoccupied or secure are far more likely to actively seek out support when feeling stressed or overwhelmed than those who are fearful or dismissive. Therefore, being aware of the attachment styles could help to identify hospice nurses who may be struggling with mental health and compassion fatigue but are hesitant to seek help. Inadequate mental health in hospice nurses is one of the biggest contributors of compassion fatigue and, therefore, commonly results in hospice nurses exiting the field; therefore, being aware of the varying mental health levels as well as the prevalence and benefits of hospice nurses' self-care routines is imperative to providing valuable insight into the varying effects of professional burnout and compassion fatigue (Whitebird et al, 2013).

Rationale

While compassion fatigue is present in multiple nursing fields, it is clear hospice poses a significant threat to nurses working within that specific environment. This is

primarily due to their consistent proximity with patient suffering, death and dying, and constant communication with patients regarding their death. Additionally, the hospice nurse-patient relationship requires a deeper connection between nurse and patient which often results in consistent emotional labor for hospice nurses, further amplifying the threat of compassion fatigue. While the effects of compassion fatigue can manifest in many forms, it is typically characterized by a nurses' decline in job satisfaction, which they do not tend to speak openly about. While research has been conducted concerning the effects compassion fatigue can have on the quality of care received by the patient, there has been very little research conducted analyzing the relationship between hospice nurse-patient communication and compassion fatigue. Therefore, the following research questions will be investigated to better understand that relationship.

RQ1: What do hospice nurses report as the consequences of compassion fatigue for themselves, their colleagues, and their patients?

RQ2: How do hospice nurses think compassion fatigue influences the way they communicate with their patients?

CHAPTER 2: METHODOLOGY

Methodology

This study worked to identify a connection between compassion fatigue and hospice nurse-patient communication. To gain a comprehensive understanding of this potential connection, in-depth semi-structured interviews were utilized to allow participants to create a narrative surrounding their experience. Data was analyzed utilizing the thematic constant comparison method. Data collection began immediately following the institutional review board approval.

Participants

Participants for this study were hospice nurses. There were no requirements beyond being a hospice nurse to participate in this research study. Snowball sampling and purposive sampling was utilized to gather the sample. A personal contact of the researcher reached out to hospice nursing friends and acquaintances and asked them to participate in this study. The contact provided participants with the researcher's contact information if they were willing to participate. Additionally, local hospice organizations were contacted and specifically asked to contact their employees and let them know about the study as well as spread the researcher's contact information. Lastly, after each interview the researcher asked the participant to spread the word about the research study and to have those interested contact her. In order to understand the research questions under investigation, a minimum of seven semi-structured interviews were conducted. The study had eight participants, each female, ranging in hospice experiences from a few years to fifteen plus years. All participants consented to being recorded.

Interviews

Once participants indicated their interest to participate in the study, an email was sent that included drawing prompts to encourage more open conversations and an informed consent form. Then, a time and place were set for the interview. Interviews took place in a private, quiet area of the hospice institution, a private area outside of hospice, or on the phone. Interviews lasted forty-five minutes to an hour and were semi-structured as a way of encouraging participants to expand upon their own experiences, encourage the formation of narratives, as well as to better understand the experiences and perspectives of the participants. In order to better help participants, express their feelings associated with the work they are doing, as well as the effects that work can have on their life, their colleagues' lives, and the care of their patients, there was also a drawing component to the interview process. This was to make participants feel more comfortable with the researcher as well as to encourage them to reflect on their experiences before the interview.

There were 8 semi-structured interview questions and 4 drawing prompts. Interview questions were open ended and formatted in such a way to encourage the creation of narratives. The first few questions were meant to build rapport with participants and to help them feel comfortable. Next, questions analyzed the challenges associated with their day-to-day job and the effects those challenges can have on stress and fatigue. Questions then focused on the way stress and fatigue affect the participant's job, the care patients receive as well as the way they see stress and fatigue affecting their colleagues. The final two questions focused on any self-care activities participants engaged in as well as an ending question asking if there is anything else the participant

thinks the researcher should know (Appendix A). Drawing prompts and questions were formatted in a way to encourage participants to reflect on their experiences in hospice as well as their experiences with compassion fatigue. However, it is important to note, the term “compassion fatigue” was not explicitly used in an attempt to avoid the use of unnecessary use of jargon as well as avoid confusion (Appendix A).

Participants brought their drawings with them to the interview and were asked to discuss their responses to the prompts, this was part of the recorded interview and participants’ descriptions were transcribed and were also analyzed through the use of first and second-level coding. Therefore, participants’ drawings were analyzed, essentially, by the participants themselves and lent a significant amount of insight into the interviews themselves.

Data Analysis

The data was coded using the constant comparative method (Glaser & Strauss, 1967). First, during the data immersion phase, each transcript was read many times over to achieve a complete idea of the experience of the participants, as well as ensure any themes discovered were soundly grounded within the data. Second, primary cycle coding was used to begin to identify common themes in the data. This consisted of going through each transcript, line-by-line, and identifying first-level codes. These were components of the data that were descriptive or focused on a process; this is what Tracy (2013) refers to as determining the “what” present in the data. In this stage, codes such as “administrative issues”, “balance” or “patient pain” were used as examples of primary-cycle codes. Then, secondary-cycle coding was used to organize the codes found in the primary-cycle into interpretive concepts. Some examples of secondary codes were “good death” or “feeling

underappreciated”. This is where patterns were identified, and the data began to come together to form themes. To adequately identify themes, each theme must adhere to three criteria, “recurrence, repetition, and forcefulness” (Owens, pg. 275, 1984). Recurrence will be classified as instances where participants repeat what previous participants have said, just in different words, repetition will be noted when the same phrases or words continue to come up, and forcefulness will be noted by participant’s vocal emphasis. Singular, impactful quotations will be isolated and used within the study’s results to further reinforce the implications of the study. Utilizing constant comparative method to better identify participants’ experiences and emotions helped to ensure a complete representation of the communication practices used by participants was provided.

Ethical considerations

The researcher received approval from their institutions Institutional Review Board before conducting research. Due to the nature of the study, the researcher was conscientious that no HIPPA regulations were breached. Therefore, the researcher instructed participants to maintain patient privacy when reflecting on experiences with patients. Additionally, there is a concerning trend among health professionals consisting of waiting until a crisis arises to convey ethical concerns (Pavlish, Brown-Saltzman, Fine, & Jakel, 2014). Keeping this in mind, it was crucial to formulate a continuous communication plan with hospice staff when conducting research to ensure no ethical issues were developing regarding the research being conducted. Being aware of these ethical considerations, as well as keeping consistent communication with hospice nurses helped to protect the subjects of the study, avoid any unethical situations, and maintain the integrity of both the study as well as the researcher.

CHAPTER 3: FINDINGS

Hospice Nursing

Being a hospice nurse requires a special type of person. This idea, or some version of it, was mentioned by each participant during their interviews. To them, a hospice nurse is someone who is wholly dedicated to their patients in such a way they often neglect their own needs in terms of taking a break. Betsy, a home hospice nurse for thirteen years, explains her unique ability to do her job,

I don't think anybody else can pick up my torch and take it when I'm taking vacation or whatever. I have canceled vacations when somebody was actively dying because I needed to be there when they died... Nobody can take care of my patient like I can

Betsy's apprehension to leave her patients was present throughout the interviews with Stacy stating, "caregivers are the worst at caring for themselves". This combination of a lack of self-care and an immense dedication to patients often results in a struggle to balance personal and professional life; multiple participants noted the difficulty in keeping the two separate. Shannon explains, "It's impossible for me to keep the two separated, so much of my life consists of my patients and it's hard to let them just be work because they're not just work". Shannon's experience is indicative of the realities the hospice nursing as a profession presents; hospice nurses are tasked with caring for patients at the end of their life, as a result, they are responsible for multiple aspects of comfort. Often, hospice nurses are there to see patients and family members through loss, fear, and pain; this can quickly drain hospice nurses and result in a mental and physical

exhaustion. However, despite the challenges that come with being a hospice nurse, each participant noted their love for their work and the sense of reward it provides them. The pervasive nature of this particular role, whether explicit or implicit, works to exacerbate the challenging effects of the hospice environment to corrode nurses' energy and patience.

Hospice Nurse Roles

Hospice nurses traverse multiple roles when dealing with patient cases; the demands associated with patients in various states of end-of-life care, families in multiple stages of grieving, and various home settings result in the need for the hospice nurses to fulfill each unique requirement. Participants did not report engaging in each type of role discussed during each visit but rather, adapted the role they played to the situation in which they found themselves. Most participants reported playing a myriad of roles during each patient visit. The primary nurse roles presented were, in no particular order, the hospice nurse as a death guide for the patient, a death guide for the family, a provider of comfort drugs and an advocate. In an attempt to provide context for the situation in which hospice nurses find themselves, various roles are presented in relation to the challenges associated with the different roles. These roles not only challenge the hospice nurses' abilities in terms of emotional fatigue, but also can make compassion for patients difficult; while no hospice nurses mentioned any ill will towards patient themselves, they did often speak about how each visit would impact them both mentally and emotionally. Eva explains how her exhaustion often affects her job and how, at times, she is forced to just fulfill the medical side of the job, "if it's been a long day or it's getting close to the end of the week, then I'm usually a little short. Sometimes I'm just focused on the

medicine and how they're feeling. Strictly the job stuff'. Eva's quotation highlights the difficulty of being a hospice nurse; other health care professions consist of strictly the "medical stuff" however, when hospice nurses focus only on the medical side of their job, they feel guilty and as if they are not doing their job to the best of their ability. This was further exacerbated by the challenge to adapt the roles being played to the needs of each patient; hospice nurses never played one role but, instead, played multiple roles at a time. Stacy, a hospice nurse for two years, explains,

As a hospice nurse you're not just the nurse like you're a social worker, you're a chaplain...I mean stuff you would just never imagine as a nurse you would be doing. I mean it's very challenging trying to offer what your patients and the family needs.

Stacy's explanation embodies the nature of what it means to be a hospice nurse, and how attuned nurses must be to not just their patients' needs, but the needs of family members as well. These various roles each require a different levels and types of compassion from hospice nurses; therefore, hospice nurses must tailor their compassionate care to each unique patient situation dependent on the roles required by the situation.

Hospice nurse as a death guide for the patient. While, as previously mentioned, hospice nurses are responsible for maintaining quality of life for terminal patients, they also view themselves as responsible for maintaining the quality of the end of life as well. As a result, hospice nurses often view themselves as a guide for the patient and feel it is their responsibility to ensure a good death. With this role comes a series of responsibilities including but not limited to physical relief, mental relief, and the

resolution of family issues resulting in stress on the patient or a hesitancy to let-go and pass away.

Bonnie, who is going on her tenth year in home hospice, speaks about her obligation to ensure her patients' physical comfort explaining, "I'm helping to make sure my patients end their life as comfortably as possible". Bonnie went on to explain the role the hospice nurse plays is complicated; the nurse is not hurrying the end of life, but they are playing an integral part in ensuring the end is as peaceful and free from fear as possible. Furthermore, she highlights that most hospice nurses are involved from the beginning to the resolution of the end of life process and, therefore, is seen as someone who is meant to provide guidance.

When dealing with patients who are actively dying, hospice nurses must visit these patients each day along with other patients. These are typically the patients who have the least amount of time left and are, therefore, more in need of a guide. Betsy, in her thirteenth year of home hospice work, explains her commitment to these patients when stating,

I'm this- hospice nurse willing to sacrifice and take this journey with each of my clients. When I sit down and I do their admissions, I make a promise that we're going to walk this with you... I have canceled vacations when somebody was actively dying because I needed to be there when they died.

Nurses must be constantly checking on their pain medication needs, provide the family with any additional support they may need and ensure the patient is receiving their hourly

medication once they leave to go to their next visit. Eva explains how her role as a guide is enhanced with patients who are actively dying,

They actually get visits every day. Even on the weekends, they have to get visited every day and that's more to make sure that their symptoms are controlled. That they don't have uncontrolled pain, discomfort, dysemia.... Make sure they have enough medications because of course at that time, most of the time people are on medications every hour.

Eva's experience highlights not only the stress of maintaining patient comfort, but also that she is being a good guide for the patient. As end of life gets closer, families tend to become more upset and overwhelmed; this can stress the patient, hindering their quality of life. The quintessential goal of hospice care is to ensure as high a quality of life as possible until their patient passes. Therefore, when the quality of life becomes threatened by a family member, hospice nurses view it as their responsibility to step in, mediate, and prevent the threat from effecting their patient.

Mentions of various types of deaths were rampant in participant interviews; each patient story shared contained some commentary on the quality of death experienced in the end. Attached to the assessment of a patient's death was often a judgement of how that participant viewed their role in determining the quality of death. When sharing stories of a peaceful and painless death, nurses viewed the patient case as successful and an example of an instance where they had done their job well; however, when sharing stories containing a painful and agitated death, nurses viewed the patient case as flawed and did not feel it reflected their nursing abilities in a positive light.

When caring for someone at the end of their life, most want to ensure the end comes in the most peaceful way possible. The concept of guiding the patient to a good death was pervasive in each discussion with participants; without being prompted, each participant mentioned, in some way, the importance of ensuring their patient died a good death. Essentially, based on participant input, a good death can be defined as a death where the patient is free from pain and fear, comfortable, and accepting of death; it is also typical of a patient to be of old age to have experienced a good death. When hospice nurses recalled patients who were younger, or close to their own age, regardless of the type of death experienced, it was considered a bad death. Stacy references this concept, "...this is just so hard when you've got a 45 year old person who has a terminal diagnosis and there's nothing you can do." Elderly hospice patients were the norm for Stacy; therefore, when coming across patients considered young or middle aged, Stacy felt guilty due to her inability to halt the end-of-life process. Additionally, Betsy recalls her experience with a seventeen-year-old pediatric hospice patient,

I'm doing this thing, I'm loading him up with medicine to try to make it more comfortable, and I do this thing that I have to do and at the end he says, "Thank you Ms. Betsy." Tears and all, still thanking me for what I'm doing to him, even though I'm hurting him.

Betsy would go on to mention this patient was the same age as one of her children and she struggled with treating the patient due to the similarities between the patient and her child, it was difficult for her to separate the two. The pediatric patient passed away comfortably and, had he been considered elderly, it would have been considered a good death. However, due to the young age of the patient and the connection to her child,

Betsy felt guilt and struggled with accepting the death of that patient. Hospice nurses place the utmost importance on providing a good death and, if a patient does not experience a good death, then these nurses they did not care for the patient to the best of their ability. When speaking about the many goals present in hospice care, Stacy mentions, “They don't want to have pain. They don't want to have shortness of breath. They don't want to have a long drawn out death and...they don't want it to go on forever”. Stacy’s explanations of the goals of hospice nurses highlights the prevalence of the concept of providing a good death and its embedment in the culture of hospice care.

While a good death is something for which hospice nurses are constantly striving, a bad death is something against which all hospice nurses are united. A bad death can be defined as any type of death consisting of pain, fear, anxiety, or discomfort of any kind. While the term bad death was never explicitly used in interviews, participants gave multiple examples of situations where a patient’s death felt like a failure to the nurses. Eva states, “...his stats would flow no matter what we did. We couldn't get his breathing to a comfortable-- He actually died of air hunger and it was terrible”. After conveying this story, Eva was quick to get to the next question, this memory of a patient who died in a way that is undesirable seemed to shake her to a point where she did not want to dwell on it any longer than needed. While a bad death makes the loss of patient exponentially harder for hospice nurses, a bad death can also negatively affect hospice nurses’ perceptions of their jobs due to the responsibility they feel for their patients. Betsy likens the feeling when a patient is having a bad death to, “feeling like a fat, juicy plum before you enter that journey, and at the end you feel like a prune... It sucks the life out of you”. Considering her perception of a nurse’s job to make death look pretty, it is

understandable that, when a death is not pretty, there is a perception of failure. This can work towards further exacerbating any exhaustion occurring as a result of the other responsibilities associated with the hospice nurse profession. Furthermore, the socialization around hospice work regarding the need to remain detached from hospice patients puts nurses in a precarious position regarding their emotions surrounding patients suffering from a bad death and the need to remain professionally distant.

Overall, the work in which hospice nurses engage to help to ensure a good death do not just affect their perceptions of their job but can also cause guilt if a patient did not die in way perceived as good. Therefore, hospice nurses often must cope with this sense of responsibility, as well as a lack of control. This role was present in each interview conducted; participants take their job seriously and believe, while not explicitly mentioned in their job description, it is up to them to ensure their patients pass in the best way possible. Consequently, when a patient experiences a bad death, nurses often feel they have failed at their job. This can quickly dishearten nurses and exacerbate the challenges of engaging in compassion care for each patient.

Hospice nurse as a death guide for the family. The responsibility of death guide is not limited to that of the patient; in fact, many hospice nurses mentioned the view that family members are an extension of their patient. Hospice nurses therefore feel culpable for providing the family with a good death experience just as much as the patient. The role of a death guide for family members differs from that of the role of death guide for the patient due to the amount of emotional labor, or managing of others' emotions, in which hospice nurses must engage. While the nurse is responsible for the physical care of the patient, hospice nurses feel exclusively responsible for the emotional care of patients'

family members. Therefore, fulfilling the role of a death guide for family members is primarily an emotional role.

While hospice nurses must work to ensure their patients do not feel alone on their end-of-life journey, the patient's family must also feel as if they are being guided. Stacy highlights this notion by explaining her role as an "angel"; she explains, "the nurses are more like the angels so to speak to the family because they're the main person that comes down and makes med changes and makes suggestions". While most health care settings are far more concerned with the patient, than with the patients' families, hospice nurses are consistently confronted with distraught family members in need of guidance during the loss of a loved one. This is, in part, due to the presence of family members at patients' homes. Bonnie explains her common connections with patients' families as just another aspect of her job stating, "There are usually the same people at a patient's house each time you go for a visit and so you really get to know those people almost as much as the patient... you can make a difference and help families to be more accepting". Shannon reports viewing the family as an extension of the patient explaining, "the families, they're kind of like your patients too. I mean, you're obviously not giving them medicine or examining them, but they definitely lean on you. So, you have to take care of them too". This burden of providing guidance to both the person dying, as well as the ones facing the loss of a loved one places the nurse in a precarious position due to the way they are forced to expand their scope of care and ensure they are emotionally present for both patient and family. While nurses in other health care fields are tasked with more relationship based care and maintain contact with certain patients and their families well after they have left their care, the extent to which hospice nurses continue to feel

responsible for the well-being of patients' families well after the patient has passed provide context for why hospice nurses' roles can come to include other responsibilities not mentioned in the job description.

Additionally, guiding family members through the death of a loved one is a complex role to fill due to the various stages of grief family members are in; family members would often appear to be accepting the gravity of the loss but, as the patient's death grew closer, that acceptance would falter. Eva, a fourteen-year home hospice veteran, mentions she felt responsible for a family who had not yet accepted their loved one was dying, "I took care of a man probably a month ago and his wife absolutely would not accept that he was dying, and he died and she did not do so well with it at all". Eva further explains how she viewed her guidance as a reflection of the overall quality of her work, "It kind of made me feel like a failure but I tried". Eva's guilt over not feeling as if the situation was explained as well as possible is something that has clearly stayed with Eva; she feels as though, even though the patient was in hospice care, the family member was not prepared for the death of the patient and that was, to some extent, her responsibility as well as the responsibility of others working within the hospital.

The concept of a good death is also present when guiding family members through the death of their loved one; Betsy explains her concerns about providing a good death for the family, as well as the patient,

When I explain what a hospice nurse does [it] is she makes death look pretty...Death isn't pretty. Even when you feel confident that the patient is comfortable and not feeling pain and not knowing exactly what's transpiring, it's the images that family has to live with that kind of haunt you...You're like, "Was

it ugly, when he went? Did you handle the post-mortem care in such a way that the family got to experience someone who looked peaceful, and clean, and smelt good, and everything looked pretty for them?”

In her drive to provide the family and the patient with a good death, Betsy’s perceived responsibilities extend post-mortem.

While hospice nurses are not formally required to care for family members in any way, they view family members as an extension of their patients. This results in the expansion of the role of a death guide to the family as well as the patient. Participants mentioned the bond formed with family members, with some bonds extending past the death of the patient; while some mentioned fulfilling their role as death guide in the form of providing emotional labor, others worked towards ensuring a good death for both patient as well as family members. Essentially, a good death for family members meant ensuring family members were aware and prepared for the reality of losing their loved one. Some participants described situations where family members seemed to be accepting the reality of the situation and then, seemingly out of nowhere, there would be a sudden lack of acceptance. When this occurred, and participants were unable to address it before the loved one passed, they felt as if they had failed the family members. This is where emotional labor became so prevalent; each hospice nurse is working to manage the emotions of family members. While providing a good death is crucial to hospice nurses regarding the care of their patients, it is just as crucial regarding the care of the family members of their patients as well.

Hospice nurse as a provider of comfort drugs. As previously stated, the goal of a hospice nurse is to help the patient maintain the highest quality of life possible for the

longest amount of time, ideally up until the patient reaches the end of their life. While patients can often require drugs for anxiety, or to provide respiratory relief, the majority of the medical requirements of the job are surrounded around pain management and comfort drugs. Comfort drugs, as referred to by participants, are often narcotics and carry a stigma with them both in the health care world, as well as in the world outside of health care; as a result, hospice nurses often recall feeling conflicted about providing comfort drugs in the beginning of their careers. But, as their time in the field increased, they became more understanding of the necessity behind the use of these drugs. However, the need to make others comfortable with the use of such drugs still remains.

One of the key reasons behind negative perceptions of the use of comfort drugs is a lack of education. This primarily stems from a misperception of many comfort drugs as drugs that are used to kill individuals. This originates from a popular practice from the past; Eva explains the link of this past practice and how it has worked to shape current beliefs about the use of these comfort drugs,

Sometimes it takes some families a little while to get comfortable with giving their family member Morphine or Ativan or Haldol because there's that stigma with Morphine equals death in this situation...if you take it back years ago, if a person was dying, their solution was to knock that person out till they died.

Eva further explains how she works towards provided education to these families regarding the use of comfort drugs and narcotics; this often consists of her reemphasizing her job responsibilities regarding how she is meant to provide quality of life, but not rush death. This typically provides some respite for the families but, as Eva states, it often

takes family members time to be fully comfortable with the use of narcotics such as Morphine.

However, family members are not always accepting of this education; Bonnie reflects on her struggles to educate family members about the use of these drugs when she explains, “Certain personalities can resist explanations about why it's being used, and how it really does not speed anything up or slow anything down.” Bonnie’s struggle to educate family members further highlights a lack of education not just regarding the use of comfort drugs, but also regarding the overarching goal of hospice as a profession. Underlying the families’ hesitancy for the nurses to administer more drugs that will ease patients’ pain is the fear that, because hospice services are provided at the end of life, hospice nurses are somehow working towards facilitating a quick death. Bonnie expands on her education process when she explains, “The person's disease process is always just taking them to where they need to use these medications to be comfortable.” Highlighting the importance of the medications to the patient’s comfort helps hospice nurses to reframe the stigma surrounding these types of drugs and allows for any potential guilt the family members feel in providing their loved on with the drugs in questions to be subdued.

While hospice nurses have to actively work with family members to break the stigma associated with the narcotics most frequently used to provide comfort, these nurses also recall feeling hesitant in the early stages of their careers to use the same narcotics for which they advocate. This stems from a perception present throughout the health care world deeming the use of narcotics as morphine as doing more harm than good. Stacy echoes this sentiment when talking about her own experiences coming to

hospice and the perceptions others have of her job stating, “It’s like hospice and morphine are like the worst words you could ever use”. Within this one quotation, Stacy explains the struggles associated with professional perceptions regarding her job, and one of the most frequently used tools of her job. Essentially, morphine is only used in situations where nothing else is providing relief and, even then, providers are still hesitant to use morphine. This perception often spills over into the hospice field and will cause hospice staff to resist the use of morphine when caring for patients nearing the end due to the fear of being the provider who killed the patient. This misperception of both the use of morphine in hospice, as well as hospice care as a whole can be identified as a cause of a lack of education within the entire medical field. Stacy explains the origin of her own misperceptions,

But there’s a huge educational, some piece missing with what morphine and lorazepam and you know all the comfort medications are. I mean I was one of those nurses in the beginning who didn’t want to use morphine. The first comfort care patient I had I panicked I was like I am not administering that medication because I don’t want to be that person who kills that patient. But it was just not being educated because we didn’t spend a lot of time on hospice and end of life care.

Stacy’s hesitancy to use comfort drugs, even once she was in the hospice field, highlights how drastically this lack of education can affect not just nurses, but also patients.

While hospice nurses have to overcome and fill gaps in education regarding comfort drugs, they also have to work to persuade family members, patients, and even colleagues to be comfortable with utilizing and receiving comfort drugs. While providing

education can help to make individuals more This can be complicated because there are times when the only thing that will relieve a patient's discomfort is a comfort drug with which they are uncomfortable receiving; this places the hospice nurses in a precarious position due to the way they have work with the patient to help illustrate the drugs will work to simply relieve their pain, and will not kill them. This is what Jenn, a hospice nurse for two years, experienced when she shared,

I had this patient. He was really in a lot of pain and none of the other stuff I was using would even make a dent in his pain. He was very clear from the beginning that he didn't want any narcotics, so I was giving him everything I could, but it just wasn't working. I told him I was going to see about getting him morphine and he yelled at me 'hell no!' so I sat with him and told him that is going to be the only thing that's going to help him. Finally, after what felt like forever he let me call for it and then administer it and he almost immediately felt better.

Jenn's experience of having to not just rely on her ability to educate, but to also persuade in a time where a patient is in significant pain and refusing help. However, in situations where nurses are unable to persuade patients to feel comfortable with receiving narcotic pain medication, nurse often feel as if they have failed to serve the patient. Shannon reflects on a situation where, despite her efforts, a patient could not be swayed to accept the comfort drugs offered,

I do have this one story where a patient was almost paranoid about the intense drugs, Morphine and those kind of narcotics, and she was in I mean really a lot of pain. But I could not, no matter what I did, convince her to take, what I call the heavy stuff. Her daughter was even trying to convince her, and she wouldn't take

it. She died a few days later and I am almost positive she was in a lot of pain when she passed. I feel really bad I couldn't convince her to let me help her.

While Shannon did everything in her power to make sure her patient had what she needed to be comfortable, the patient was not comfortable with narcotics. This stuck with Shannon and made her feel guilty, even though there was nothing she could do to better help the situation. She felt powerless.

When analyzing the job of hospice nurse the most fundamental aspect is physical care; in order to achieve this physical care, comfort drugs must be utilized. Participants mentioned their experiences regarding providing comfort drugs and explained the various ways they overcome stigma associated with comfort drugs. Most hospice nurses explained the need for educating and persuading patients and family members who did not feel comfortable with the use of comfort drugs due to a fear of addiction or a perception associated with the use of comfort drugs and the belief that using these will hasten the death of a patient. When these concerns arose, participants continuously mentioned engaging in behaviors that allowed the patient to receive the comfort drugs needed without any guilt or shame from stigma or family pressure. This role forces hospice nurses to engage in a level of tough love with their patients and their families to ensure they are able to receive as much physical comfort as possible and, if they choose not to accept comfort drugs, they are fully educated regarding the reality of the use of these drugs at the end of life.

Hospice nurse as an advocate for comfort drugs. While hospice nurses must work towards ensuring their patients and the families of their patients are comfortable with the use of comfort drugs, in situations where there is discord between the patient's

wants and the wants of the families, hospice nurses must step in and advocate for their patients through the advocating of comfort drugs. This can be argued as the combination between both education and persuasion to ensure the patient's needs are being met in a timely and adequate manner.

Jenn shares a story of a time when the patient confided a need for morphine,

I had one family that was just frustrating. They were constantly talking about how bad those drugs like morphine, the narcotics, are and how they didn't want to give it to my patient because they didn't want my patient to die a junky. But the patient was in really a lot of pain and pulled me aside during one of my visits and was like, "I know they don't want me to have it but if it's going to make me feel better, can you just not tell them I'm getting it?" ... I had to tell that family that whether or not the patient died a junky didn't matter because they're in pain and it's not fair to leave them that way.

Betsy's act of advocacy helped to highlight the need for the family to understand how much pain their loved one was in helped the patient to receive the relief from both pain as well as perceived judgement from family members.

However, this advocacy does not end with family members, the negative perceptions regarding common comfort drugs pervading the medical profession are something hospice nurses must also confront. Shannon shares an example of a time where advocating for her patient meant challenging a medical director, an individual who was her superior,

We used to have this medical director who was totally against the use of morphine, he thought it did more bad than good, I had this patient who couldn't get his pain management under control...So, I went to [the medical director] to get an order for morphine and he wouldn't give it to me. I had him come with me to visit that patient the next day to see how much pain he was in and, after seeing him that way, I got the order.

Oftentimes, supervisors such as medical directors, are not seeing patients as often as the hospice nurses; this can result in a lack of awareness regarding the level of pain hospice patients can be experiencing. By having the medical director accompany her on the visit to her patient, Shannon let the reality of the situation serve as the primary advocate for obtaining the order for the morphine. Medical directors are different from family members due to their medical training and are, therefore, well educated about comfort drugs, but the stigma associated with these medications can easily overshadow the education when it comes to patients nearing the end of their life. Due to the sense of duty to their patients, hospice nurses recognize the need to advocate for their patients; especially if it means their patients are able to enjoy a painless death.

Unique Challenges for Hospice Nurses

While nursing as a profession is one consisting of more care centered work, hospice nursing presents unique challenges to those involved for a multitude of reasons. Most participants noted the nature of hospice work to require a certain type of person; this is likely due to the level of caring in which a hospice nurse must engage as well as the various levels of autonomy that come with being a home hospice nurse. All participants had at least three hospice patients who were in the home, while some

participants split their time between home hospice and hospital hospice, all were involved in home hospice in some way. This results in a series of requirements from the nurses working in the environments and, as a result, can be quite challenging to adapt.

. Most participants defined themselves as maintaining a professional distance from their patients, or not allowing themselves to get too close to their patients or the families of the patients. This presents a challenge due to the emotionally involved work the nurses are doing; it is not become personally invested in the individuals for which these nurses are caring. Even the difficult patients, Jenn explains, are ones with whom a connection can be formed and maintained,

It's almost harder when you get a patient that is difficult, and you end up really caring for them not just as a patient, but as another human too. That makes everything so much harder because...you want them to feel good and be happy, so when they are in pain or are feeling anxious or anything it breaks your heart.

But it's not supposed to, it's supposed to be just another patient. That's how we're trained.

When asked to expand more on her struggle associated with forming strong bonds with patients, Jenn linked her conflict with the socialization process of nursing school.

Essentially, when going through training, nurses are encouraged to do the job to the best of their ability while still encouraging them to keep their personal lives separate from their work lives. Therefore, a tension exists hospice nurses must navigate in order to feel as if they are accomplishing their professional objectives in a way that pleases both their colleagues, as well as their patients. While many participants came to hospice care from nursing fields containing death, many were not prepared for the types of connection

fostered within the hospice environment. Shannon, who began her nursing career in the ICU, states,

I was in ICU, like I said, and so I was seeing people die pretty regularly. So that's pretty much the same. But in this position, you form more connections with these patients, when they die it definitely affects you more. That's the hardest part for me. I wasn't used to getting to know my patients so well and so I start in hospice and I start to really love these people. And it's not just the patients, it's their families too. You are serving them just as much as the patients, so you form connections with all of them. That's the main difference is the connection. It's almost impossible to not form a connection with them.

Shannon's experiences highlight the previously stated nature of the work in which these nurses are engaging and the way in which that environment provides a considerable challenge in terms of remaining emotionally detached. Stacy echoes this concept after reflecting on the ways patient struggles can heighten the stress and fatigue experienced by hospice nurses, "Honestly it makes it worse which is why I try to stay detached." It is interesting to note her emphasis on her desire and attempt to stay detached, yet after providing this quotation proceeded to share another example of a patient with whom she formed a relationship with the patient as well as the patient's daughter that has remained even after the passing of the patient in question. Stacy's experience personifies the constant tension present within the hospice profession; Stacy voices her intention to remain detached and depersonalized from her patients as a way to demonstrate her awareness of the "standard" that is set as a result of the socialization occurring in nursing school, but ultimately does what she think is the best thing for her patients. In this case, it

is neither promoting nor preventing the formation of bonds between nurses and patients. Furthermore, in doing so, Stacy allows for organic and genuine connections to be formed when treating patients.

Throughout the process of training to become a hospice nurse, the message of the importance of maintaining professional distance pervades the socialization of all individuals in nursing school. However, given the emotional nature of end-of-life care, hospice nurses find it difficult to maintain that professional distance; as a result, hospice nurses find themselves engaging in almost constant emotional work in an attempt to monitor their own emotions and prevent themselves from forming a bond that would be considered unprofessional. Despite these attempts, many participants identified multiple instances in which a strong bond was formed with either a patient or a family member or both; with each of these examples came a sense of guilt regarding that bond and a feeling they had done something wrong in creating that genuine bond. The requirement of constantly checking one's emotions quickly becomes exhausting and navigating such a tension can quickly result in fatigue regarding the care provided for patients. Additionally, this challenge demands hospice nurses show enough compassion towards their patients to ensure their patients feel comfortable, but also forces hospice nurses to ensure they're not showing too much compassion.

Hesitancy to take a break. Hospice nurses are not only tasked with attempting to refrain from forming connections with patients and patient families, but also feel the need to resist taking a break to care for their emotional well-being. Hospice nurses view their need for a break as a sign that they have allowed themselves to emotionally connect with

patients and, as a result, feel the emotional repercussions of their patients' deaths as well. Betsy emphasizes this guilt associated with needing to take a break,

You feel guilty for saying, 'I need a break.' You call it a thousand other things except for, 'I just need a break from this.'...whenever I'm worn out and can't meet [my job requirements] I feel like some kind of failure....you're either all in or all out...no one can take care of them like I can.

Betsy feels this is not unique to her but is something with which all hospice nurses must cope; allowing themselves to take the time to care for their emotional well-being is not compatible with being a hospice nurse and often results in feelings of guilt. This contributes significantly to any existing compassion fatigue that may be lingering under the surface. Jenn talks about how the guilt associated with taking a break affects her relationship with her work, "If I take a mental health day because I need time to myself to cry or whatever, I actually feel really guilty and it does it makes me kind of resent my job. Even though I love it". The need for a mental break, as Jenn calls it, is indicative of some level of compassion fatigue or burnout. Due to the level of effectiveness interventions have against compassion fatigue when implemented in the early stages, Jenn is doing the right thing by taking her mental health day; but the guilt associated with her doing so prevents her from caring for her emotional well-being. Therefore, in order to control the symptoms of compassion fatigue she experiences, it is imperative the socialization that perpetuates this guilt is altered.

As previously stated, hospice nurses are socialized to maintain professional distance between themselves and their patients; however, it was discovered this is a significant challenge that is often unrealistic given the nature of hospice work. While

many participants espoused the connections formed with patients and family members as well as the emotional work in which they constantly engaged, they also mentioned their own reluctance to take breaks from their jobs. While many participants voiced this as a result of a feeling of ownership to their patients, this hesitancy was also exacerbated by the aforementioned socialization. Essentially, participants described their common view that the need for a break is a result of allowing themselves to form close bonds with patients and, if an emotional or mental break is needed, they have themselves to blame for failing to maintain appropriate professional distance. This challenge works to have an immensely negative effect not only on hospice nurses' ability to engage in compassionate care for their patients, but also can quickly hinder their relationship with their work.

Autonomy. While autonomy can at times be considered a good thing, it is important to note that autonomy in the hospice setting results in very few outlets to vent about difficult patients or feelings. Participants note the large amount of time each spent in their car driving from each patient visit to the next and making runs by the pharmacy to ensure their patients have all of their medication; this creates an isolating work environment that does not allow for much interaction with colleagues. This can be harmful due to the way it forces hospice nurses to make sense of their feelings, cope with their last patient, and make sure they do not bring in any feelings from the patient before. Cassie, who has been a home hospice nurse for eighteen years, explains her efforts to not let bad patients effect the care provided to other patients,

“I don't bring things to another patient's room or to another patient's house...

Now when I leave that room I might be bawling or might be crying. But I don't

take it to the patient or the family... We really can kind of overcome and turn it off

Cassie's experience is indicative of how crucial it is to have a space and support system that allows for decompressing and sense-making of patient experiences. Many nurses mentioned the value of the ability to vent with colleagues when the opportunity presented itself. Stacy explains,

...my co-workers are so great. Like we all vent...I really honestly am blessed that I have such amazing support because if I didn't and it was just me and I had to hold it all in I think that I would probably never survive.

While Stacy was one of the nurses who visited only a few patients in home hospice settings, it was abundantly clear throughout her interview the benefit her colleagues presented as a support system. Similarly, those who primarily worked in home hospice settings, with most of their time being spent alone valued opportunities to vent, but opportunities were not available often. Bonnie, a nurse who spends minimal time each day in the office stated, "There's not as much [venting] as there would be if we worked in the same place all the time, because our time in the office is limited... We have team meetings actually where we discuss all of our patients." While team meetings are an opportunity to receive support and advice regarding certain patient cases, it is not a conducive environment to allow your patient frustrations to be made known. While the coping mechanism of tuning out one's emotions to not allow the feelings from the past patient to have an effect, the emotional labor requirement can easily become overwhelming. Many nurses also noted their cars as a safe space to which they could retreat when preparing for the next patient with some even referring to the cars explicitly

as sanctuaries. Cassie mentions the value she places in her car as a place to escape from the stresses of her hectic days, “my car is my sanctuary. Because you live there...you basically have a hospital in your trunk.” Cassie understands the importance of having a space where one can take a deep breath and process the latest visit when doing visits on one’s own. Cassie continued to explain how her car is her office and it is one of the only places that serves as both a place for work, but also a place for personal contemplation.

While hospice nurses can enjoy the autonomy their job offers, it can also be challenging in terms of the emotional work required by hospice nurses who spend most of their days on their own. Participants mentioned their efforts to ensure any emotional reactions caused by other patient visits did not bleed into other patient visits. As a result, compassion becomes challenging for hospice nurses due to the way in which their autonomy can cause a feeling of loneliness. The stress caused by these patient visits can quickly result in compassion fatigue due to the exhaustion from the emotional work. This emotional work in which participants viewed it required they engage was often broken when presented with an opportunity to vent or talk with colleagues; therefore, hospice nurses viewed opportunities to communicate with colleagues as an opportunity to take a break from the emotional work and converse about difficult patients and other challenges associated with hospice.

Flexibility. Hospice work is rarely ever predictable; therefore, nurses must be prepared to change their day at a moment’s notice. When asked to describe a typical day in their job, all participants explained there was no such thing; while hospice nurses go into their days with a rough, preconceived plan in their minds, there is always something that will redirect their day. Flexibility is, therefore, a crucial component and often a

challenge commonly presented in the work of a hospice nurse. Stacy explains how her ability to remain flexible plays a crucial role in her day-to-day work, “So hospice is a kind of an ever-changing thing... it's challenging to figure out what your specific role is going to be based on what families need.” In this instance, Stacy must be flexible in terms of the various roles she is playing. While she may strictly be the hospice nurse in one patient visit, she could be a spiritual guide and grief counselor to patient and family in the next scheduled visit. Additionally, patients who are actively dying require the most flexibility; the majority of participants expressed a strain they were experiencing due to their case load, this strain was further exacerbated the higher the number of actively dying patients. Actively dying patients are those that require constant care and also require daily visits. Jenn explains how the recent inclusion of multiple actively dying patients into her case load affects her daily routine,

Your days really feel like puzzle pieces, I think. When I have a patient who is actively dying, those are the patients you see every day, then that is automatically one more visit I have to include on top of my already big patient load. And there will be sometimes where you get a panicked call...you have to leave one patient visit early to go make sure the patient isn't in pain and has all of their symptoms under control.

Jenn's explanation of how her days are similar to puzzle pieces really works to highlight the constant recalibrating and rearranging hospice nurses must work with each day. Using the analogy of a puzzle provides an excellent image of how each visit is its own piece and, if one piece stops fitting, then the hospice nurse putting the puzzle together must quickly find the piece that does fit as well as find the correct place for the original piece

of the puzzle. If each day is a puzzle and patient visits are pieces of that puzzle, then actively dying patients can be compared to corner pieces of that puzzle; you know you have to use them and you can typically put them in their place early in the process, but that means time you are not able to spend placing more central pieces together. While actively dying patients are of crucial importance, due to their need for daily visits, they can also be a large source of stress when coupled with a heavy patient load.

Furthermore, the uncontrollable parts of the job further the requirement for flexibility; hospice nurses must be ready to adapt to each patient visit without knowing exactly what they are facing. Jess explains,

Hospice is like surgery, there is a precise nature to it, but there is also some mystery to it. Surgeons never really know what they're going to find when they cut a body open. We never know what we're going to find when we go to visit our patients. We have an idea, but we never can be sure.

This comparison of hospice to surgery works to provide a comprehensive understanding of the lack of control with which nurses must deal throughout their work days. When arriving to visit a patient, a patient could be in more pain than they have been in the past, a family member could be suddenly unaccepting of the death of their loved one, or a patient could be in need of a medication alteration that was previously unpredicted. With each surprise comes a requirement to adapt and adjust. Additionally, while patient visits require a high level of flexibility in terms of requiring the nurse to adjust care needs, resilience is required when dealing with the required channels to fulfill patient needs such as getting orders filled by physicians. Bonnie is familiar with the requirement, "Everybody's busy and sometimes you want a patient to have something timely, and you

only have so much control over that. You can make a request, but you can't necessarily speed it up.” This requires nurses to adapt to make the patient comfortable; in doing so, nurses feel an enhanced guilt due to their lack of control surrounding the patient’s needs.

The challenge of flexibility was mentioned by multiple participants and was largely due to the lack of typical day experienced by hospice nurses. While flexibility was seen as a necessary trait of hospice nurses, it was also viewed as a challenge due to the way hospice nurses are constantly having to rearrange their day. Compassion becomes difficult in such situations due to the constant reassessing in which hospice nurses must engage to ensure they are still accomplishing their daily responsibilities. However, the challenge of flexibility was also present when nurses had to wait on colleagues to fulfill prescriptions for patients’ medication needs; many participants mentioned the challenge of incorporating flexibility to adjust to doctors’ schedules and ensure they are able to fulfill all of their patients’ needs.

Administrative Issues. The work of a hospice nurse is filled with constant demands and frustrations and requires nurses to be on their toes; the administrative requirements associated with each visit place additional strain on hospice nurses. These are tasks about which hospice nurses are certainly not passionate, it was considered a necessary evil of their workload. Participants were sent drawing prompts prior to interviews being conducted one of the prompts inquired about the daily challenges participants faced in their work, and then prompted participants to draw what those challenges looked like, Bonnie took these drawing prompts and focused on administrative requirements that cause her strain,

I also drew a bunch of boxes because, no matter how crazy our days get, we still have to check boxes you know? We could have two patients pass in one day and, if we don't check our boxes like fill out our paperwork then the whole day is off and we have to play catch up. So those boxes are an important part of the job even if they are annoying.

Bonnie's view of these administrative boxes, the need to document her work, illustrates the apathy surrounding these obligations. While hospice nurses understand the need to document their work, and stay up-to-date with their paper work, so much focus on the administrative wants can cause hospice nurses to feel underappreciate and result in the perception their organization only cares about how many patients they see in a day.

Cassie voices this very concern, "They're not thinking about families and patients and how long we're going to be staying with them. They just want us to get 4 or 5 patient visits...they don't do over time because they're looking at the cost." Cassie feels she is not valued for what she does for her patients and their families, only the number of patient visits she can conduct in a day. This works to enhance a negative view of her work; throughout her interview, Cassie was clear regarding the importance of her work and how she appreciated and loved her patients. However, when speaking about the administration issues she faces, it was very apparent that was the key aspect of her profession she viewed in a negative light.

This negativity concerning the administrative issues associated with hospice work was further echoed by Jenn; while Jenn was also concerned about the amount of red tape present in her daily work, Jenn also expressed a frustration against doctors with whom she worked, "The regulation stuff is hard, yes. But what's really frustrating is when a

patient needs... a medication and the doctor who is in charge of ordering it drags their feet". Hospice nurses are in charge of calling in and determining medication changes for patients dependent on their needs; therefore, when a hospice nurse concludes an alteration in medication is necessary, it should be done so in a timely manner. However, Bonnie echoes most doctors tend to do call in the medication orders on their own time,

Other challenges may come with contacting physicians with trying to get orders timely, because they are all busy too. Everybody's busy and sometimes you want a patient to have something timely, and you only have so much control over that.

While the administrative paperwork is a large source of frustration for most hospice nurses, the frustration associated with doctors who are taking their time can cause more frustration due to the gap in care hospice nurses' patients experience as a result. As previously discussed, the responsibility felt for patients' well-being is exceptionally high; consequently, if a patient is having a hard time, nurses feel as if it is their fault regarding the patients' discomfort. Many participants identified administrative issues as a frustrating, yet necessary part of their job; this challenge works to exacerbate any exhaustion experienced and can quickly turn into compassion fatigue. Therefore, when administrative issues become too much of a challenge, hospice nurses would often report exhaustion which was often coupled with hospice nurses focusing on fulfilling the medical aspect of their job, and therefore neglecting the compassionate aspect. Doctors must be aware of this sense of responsibility and understand the importance of timely response when medication alterations are requested.

Professional misperceptions. While all of the participants identified their job as something rewarding and enjoyable, many noted their hesitancy to become hospice

nurses. This was typically due to perceptions of hospice care evident in their nursing training; Stacy mentions her apprehension towards working in hospice from the very beginning of her nursing career, “I didn't want to be a hospice nurse...I avoided it like the plague”. This was due to the perception of hospice and end-of-life care conveyed by instructors. As previously mentioned, Stacy consider morphine and hospice to be the worst words that can be used in the nursing field; towards the end of her interview, Stacy explains a part of the misperceptions are due to the lack of time spent in nursing school covering end-of-life care,

...hospice was associated with like the dark things like you don't go on that side of stuff you didn't talk about hospice. I did a one-day rotation in clinical and that was it. And I don't even think it was a full day. It was like a forbidden topic of discussion and it still is today

As a result of the neglect surrounding hospice education, Stacy's own negative views of hospice care were formed around the lack of education.

Furthermore, Bonnie discusses her disbelief at her involvement in hospice care could be contributed to one of her nursing instructors, “My nursing instructor didn't want to expect that she could see me doing hospice.” This came after being asked how she became involved in hospice; when asked about how her career came about, her first thought was about her nursing instructor who cautioned her against hospice care. This lack of education is indicative of a much larger misperception within the health care field; non-hospice health care providers view hospice as a tragic line of work. While hospice nurses are aware of the challenges that are associated with losing patients, they view their work as overall important and rewarding; however, many hospice nurses mentioned their

awareness of other health care professionals' perceptions of their job. Jess mentioned the use of dark colors for part of her drawing,

I split my drawing into two different sides one for how I see my job, and one for how everyone else sees my job...So on the other side I included a lot of dark colors and clouds and rain because when I mention my job as a hospice nurse, even to my other nurse friends, it feels like everyone is feeling bad for me. But that's not how I see it. If my job was as sad as everyone thought it was, then I wouldn't be doing it.

Jess' quotation echoes the sentiments of each participant who felt their work was perceived as negative; if it was as sad as everyone thought it is, then they would not be working in the job. This prevalence of other perceptions of the job hospice nurses do was also prevalent in Bonnie's drawing, she mentions, "So I drew a lot of black—that's mainly because of what other people think...all the other nurses I know who aren't in hospice see what I do as this really sad and hard thing." This, coupled with the attitude towards end-of-life care gathered from her nursing instructor, results in a discord between her view of the rewarding nature of her work and the misperceptions of others in the health care field. This can result in a sense of guilt associated with feelings of pride in their work; Jenn references this guilt when saying,

I know so many people who think what I do is so sad. And that's okay, it doesn't really matter, but it does sometimes make me feel bad. I mean, my job exists because people are dying, so I technically shouldn't be happy when I get a new patient, but it makes me excited to know there's someone else who I get to help.

Jenn's inner conflict hinders the pride she feels regarding the good her job does; while hospice exists to help people at the end of their life, the point of the job is still to provide care to those in need. Jenn's statement is also indicative of the mixed feelings presented by being involved as a hospice nurse; many participants, when speaking about the rewarding nature of their job, spoke about the positive feelings associated with their job hesitantly. Stacy highlights this hesitancy,

It's a rewarding job but it's also so I don't know I don't want to say it's dangerous, but it could be dangerous you know if you can't shut your brain off and you can't focus on what you need to do

Stacy's mention of the positive aspect of her job, immediately followed by a negative. This makes a hospice nurses job exceptionally difficult to manage due to the guilt surrounding any positive feelings they may experience regarding their job. Therefore, when nurses begin to feel assured in their role as a hospice nurse, they feel the need to police their own feelings due to the way in which is solely reliant on individuals at the end of their life.

These misperceptions can also result in a feeling of trivializing of hospice work from colleagues. While there was an overarching sense of comradery between participants and other hospice nurses with whom they worked, many mentioned feeling belittled by the doctors with whom they worked. Shannon, a five-year hospice nurse who conducts both home visits as well as patient visits in the hospital, explains her frustrations with one of the doctors she works with when doing hospice rounds in the hospital,

There's this one person, a doctor, and every time I see them I leave our conversations really frustrated...they always find a way to make a dig about the work I'm doing and how I'm more of a counselor than a nurse...It's not in any malicious way I don't think, but that doesn't make it less rude...I have never heard a thank you from them.

Shannon's experience highlights how those who do not understand what a hospice nurse does, beyond ensuring quality of life, can result in an incorrect assumption regarding the type of work in which these nurses are engaging. The joke regarding her as a counselor more than a nurse, while not meant to be offensive, clearly struck a nerve with her. However, while the doctor's joke to Shannon is virtually the same as Shannon telling the doctor he is more of a walking prescription pad than a doctor, Shannon does not feel comfortable explaining why the joke is problematic for fear of seeming disrespectful. Additionally, Shannon makes it clear she is not interested in receiving constant praise from her colleagues, an occasional thank you would make a considerable impact in her own perception of her job. Nurses in any health care context are commonly viewed as the ones in charge of the emotional care as well as some of the medical care; but in hospice, when nurses are dealing with those at the end of life, the perception is they are there to engage in the emotional care, and the physical care serves as a side note. Jess explains,

When you first hear I'm a hospice nurse, you imagine the person who comes in and brings juice and snacks and makes sure everything is okay...I am calling in med changes, I am scheduling different therapies, I'm doing a lot more than some medical directors do...It's not a fair judgment.

Jess' story highlights her internalized appraisal regarding her work; she knows she does more for her patients than the average nurse does, but she is having to consistently confront the perceptions she believes others hold regarding her field. Furthermore, considering Shannon's interactions with her colleague, if Jess is experiencing similar interactions with others in her organization, then her inner conflict is likely perpetuated. To combat the feelings of regarding the lack of validity of the work of a hospice nurse, colleagues within the health care field must fully comprehend the full extent of the challenges faced by hospice nurses in their day-to-day experiences.

Participants reported professional misperceptions as a large challenge of which they must face on a daily basis. While some of the professional misperceptions reported were due to the view of hospice work as dark and depressing, other misperceptions worked to trivialize the profession of hospice nurses, often diminishing them to a glorified counselor. Furthermore, these professional misperceptions contribute to a lack of education regarding the reality of hospice care. These professional misperceptions often resulted in a conflict within participants between their love of their work, and the perceptions of their work. These misperceptions can contribute to challenges of compassion within hospice work due to their belief that hospice work is a dark profession. Many participants mentioned feeling conflicted when enjoying their job; considering the enjoyment caused by feeling hospice nurses have done their job correctly, compassion can quickly become challenging.

Lack of appreciation. When caring for patients, it is common for hospice nurses to view the families as an extension of the patient; therefore, when families are unaware of the work hospice nurses do for their loved one, it can affect the nurses in a negative

way. Stacy mentions how ungrateful families, when she is tired or in a bad mood, can cause her more stress, "...to not turn around and be like seriously do you not know what I've done for you? It is really really hard. I mean it takes a lot of discipline honestly." Hospice nurses are in a complex position due to the way in which family members are able to treat them with as little or as much respect as they prefer, but nurses must ensure they remain professional to all family members, even those who prove difficult. Considering the taxing work in which hospice nurses must engage, factor in a feeling of being undervalued, and it is easy to become disenchanted with the work rather quickly. This feeling of being underappreciated effects nurses to a point where they leave their hospice work; Stacy furthers her frustrations often experienced with the families of patients, "I actually know nurses who have quit nursing with less than five years of nursing experience because of how they were treated." Stacy's statement further illustrates the toll that feeling unappreciated by family members can have on hospice nurses; considering the view of families as an extension of the patient, when family members are not grateful for the work in which the hospice nurse is engaging to provide comfort to their loved in their final days as well as the work they are performing to help family members navigate the loss of their loved one it can result in a feeling of failure. Therefore, if a hospice nurse feels as if they are constantly failing their patients, they will likely leave the field in search of an opportunity to better serve their patients.

Hospice nurses are constantly caring for family members as well as patients; many participants the reality of their work as a thankless job. This lack of appreciation from family members often worked to exacerbate any frustration participants were feeling about their work and would often result in a feeling of guilt due to the resentment

building towards family members. Nurses are often the first line of defense when it comes to family complaints; therefore, hospice nurses often feel they are giving so much to families, only to receive very little appreciation. This directly affects hospice nurses' ability and willingness to engage in compassionate care; many participants mentioned the reality of giving so much to family members, only to be treated poorly. Therefore, hospice nurses can feel reluctant to provide compassion when feeling as if their compassion will go without thanks.

Effects of Stress and Fatigue

Overall, many participants did not attest to currently experiencing compassion fatigue; however, many did describe situations where they experienced compassion fatigue as well as experiences with colleagues experiencing compassion fatigue. The key area hospice nurses saw affected by their stress and fatigue were the fulfillment of their roles.

Many participants noted when the stress and fatigue experienced in their job often resulted in a lack of ability to fully perform in each of their roles. This was due to the tendency to be less willing to spend the time needed to fulfill each role of which the patient was in need. Shannon explains,

When I'm feeling stressed or I've had a long week, I am just trying to get in and out, I don't want to spend more time at a patient visit than is necessary, which is no good. The patients need and deserve more from us...But there are times when you just can't do it.

Ensuring each role required by the patient is filled takes time; when hospice nurses are not suffering from compassion fatigue, they often find these roles fulfilling and consider them to be a rewarding part of their job. However, when negative effects of stress and fatigue have materialized, these multiple roles serve as a nuisance and a barrier between the hospice nurse and their time to rest. Hospice nurses often feel guilty when they are not able to fulfill their multiple roles and, instead, only perform the minimum required to make the patient physically comfortable. As previously mentioned, this causes nurses to feel guilty due to their lack of ability to be fully available for their patients. Jess explains,

Sometimes I have to shut down emotionally when I'm doing a visit because I'm so exhausted and it's been a long day, and I just have to get through this patient visit... I feel like, when that happens, I can be kind of short with the patient which always makes me feel bad because to me, that's not giving them the best care they can get

Jess went on to clarify the only times she feels the need to shut herself off emotionally is when she is feeling the effects of the stress and fatigue perpetuated by her job. These effects are often exacerbated in situations where a patient case load is overwhelming, or when an actively dying patient has required the hospice nurse to work overtime. Betsy shares her story of spending an evening with a patient as they died and then attempting to call into work the next day,

I was having an awful day, really stressful and at the end my husband had called just to make sure that I was okay, because I'd been out so long, and my TMJ gave me such a fit that I couldn't hardly talk to him. I was in such pain. I did my job, but I was calling in and saying, "I'm going to need tomorrow off." Because it's

three o'clock in the morning, and I've been with this family, and ... I'd worked a whole day, then been suffering this death with this family, was struggling, and it was three o'clock in the morning, and I hadn't been home. I was just calling in to say, "I don't think I can see patients tomorrow."

Betsy did not receive any sympathy from her supervisor and, instead, was given judgment and guilt for not being able to take care of her patients. However, Betsy's ability to fulfill her job was hindered due to her exhaustion. Had she gone into work the next day, she would simply be covering the basics of care instead of working towards providing the patient and family with the other roles previously discussed. Essentially, this means hospice nurses are coming into patient visits, checking vitals, asking the required questions regarding pain, and checking to make sure their patients have enough medication; when engaging in the minimum requirements of care, hospice nurses are not listening, and they are not providing emotional support. To hospice nurses, if they are covering only the basics, they are not doing their job.

Many participants mentioned the effects their stress and fatigue can have on the care they provide their patients. Cassie explains how this stress and fatigue can negatively impact patient care when causing one of her co-workers to forget important documents, "She texted me and she says. I forgot the med list and she says I'm so absent minded. I said no you're stressed. And I said that's going to cause you to forget things." This experience highlights the ways that stress and fatigue wear down nurses and can cause them to be forgetful or affect their ability to think through work problems. Bonnie echoes, "When you're fatigued, or stressed, you may just not have as much patience for those things, and you may not be able to think as clearly as you would when you respond

to them.” Hospice nurses face multiple difficulties when conducting patient visits due to their lack of knowledge regarding the current state of their patients before arriving to the patient’s home. As a result, hospice nurses must be prepared to gauge the situation their patient is currently in, and tailor their treatment plan to the current patient situation.

When hospice nurses are experiencing symptoms of compassion fatigue, this becomes an exceptionally difficult task due to their feeling of being overwhelmed. Therefore, participants report compassion fatigue as having an effect on patient care due to the way it can affect their ability to adequately think through treatment decisions and causes individuals to become more forgetful.

CHAPTER 4: DISCUSSION

This thesis revealed the complex relationship existing between hospice nurses, compassion fatigue, patients, and other colleagues. Two research questions were developed to help guide the direction of the thesis. Three themes were revealed as a result of the interviews with participants, hospice nurse roles, unique challenges of hospice nursing, and the effects of stress and fatigue. This last chapter focuses on the way in which the research informed the research questions and what implications the findings hold, professional applications of the research, limitations, and opportunities for future research.

Research Question 1

The first research question sought to understand what hospice nurses reported as consequences of compassion fatigue for themselves, colleagues, and patients. Participants identified a number of consequences regarding each group. First, many hospice nurses report compassion fatigue significantly negatively affects their own perception of their work. It is important to note, however, none of the participants used the word compassion fatigue explicitly. Instead, the effects of compassion fatigue can be identified by the symptoms of stress and fatigue presented by participants. Many hospice nurses mentioned the feeling of importance their job brought them as well as how rewarding the job could be; however, participants would often present a sense of guilt when reflecting on the positive aspects of their job. This causes hospice nurses to have a complicated relationship with their work. Nurses feel guilty for enjoying their work due to the way in which their job requires individuals who are dying. Additionally, when they began to experience the effects of compassion fatigue such as mental exhaustion, agitation, or

depression, they would often begin to resent their job and the multiple components of care associated with it. Difficult family members of patients proved to further this resentment due to the dynamic present allowing family members to treat hospice nurses however they see fit, with the hospice nurses unable to stand up for themselves, or correct family members. This can be seen as a component of emotional work; essentially, hospice nurses are required to monitor their own emotions in such situations to ensure they are not rude to patients' family members (Hothschild, 1983). Non-hospice nurse colleagues also served to exacerbate these consequences; this primarily occurred when participants felt unappreciated for the work they were doing, or felt others viewed their work as easy. Other consequences of compassion fatigue affecting participants were perceived gaps in care; when participants reported feeling overwhelmed by the stress and fatigue in their daily routine, they often linked those feelings to a higher tendency to forget to process a medication change or forget to make note of an important patient characteristic. This is of great importance due to the effect hospice nurses believe compassion fatigue has on their own care of their patients (Amenta, 1984).

Second, the perceived consequences of compassion fatigue on hospice nurse colleagues were similar to the consequences participants perceived for themselves; however, when discussing how compassion fatigue materialized in others, discussion would often turn towards a judgmental tone towards the colleague being discussed. When reflecting on how participants view stress and fatigue affect their colleagues, participants would often speak about the clear disinterest presented by others and how important it was for them to make sure they are taking care of themselves. This resulted in a perception that those experiencing compassion fatigues should have worked to prevent it

from affecting them; this can be dangerous because it can often result in a lack of communication regarding feelings of stress and fatigue until it has become so bad the nurse decides to leave the hospice field. While many hospice nurses were confident in their ability to spot compassion fatigue when it was taking a toll on their colleagues, the symptoms presented were often indicative of severe compassion fatigue when an intervention would likely not be effective (Carter, Dyer, & Mikan, 2013). Furthermore, the venting sessions present in many of the participants work places seemed to be helpful but, if multiple hospice nurses are suffering from compassion fatigue and resentment of their jobs, it could quickly result in enhancing the existence of compassion fatigue. While social support is a crucial component of self-care and, therefore, preventing compassion fatigue, providing a constructive space for problem solving is a more preferred option than nurses sharing negative aspects of their job with another (Alkema et al, 2008).

The consequences experienced by patients, as reported by hospice nurses, consisted primarily of care implications. These consequences were often a result of the effects participants witnessed compassion fatigue having on colleagues or themselves and the ways in which those consequences affected patients. These were things such as feeling they were not being listened to or feeling as if they were being a nuisance to their hospice nurse; additionally, forgetting to adequately reflect medication changes and schedule therapies was another consequence of hospice nurses experiencing compassion fatigue (Payne, 2001). This often resulted in what one of the participants referred to as just the medical stuff; feeling guilty for only doing the perceived bare minimum in terms of medical care meant patients were less likely to have the opportunity to present new pain symptoms to their nurse which would then result in a decline in their quality of life

until the next scheduled visit. This could be especially harmful to those patients who are not considered to be actively dying because those who are not actively dying receive visits from hospice nurses less frequently. Therefore, if a patient who is visited twice a week receives their first visit from their nurse who is experiencing excessive symptoms of compassion fatigue, according to participants, that patient will likely not receive as thorough of an exam as they would typically get which will directly affect their comfort levels leading up to the next visit from their hospice nurse which can cause the patient to act in a way that is considered difficult which can work to further exacerbate the compassion fatigue occurring within the hospice nurse. While some of the effects of the patients are a result of the reported consequences, it is important to understand the ways in which the results of compassion fatigue can negatively impact hospice patient care. Additionally, these effects are differentiated from hospice nurse interactions with patients due to the analysis provided regarding the medical relationship between the two parties.

Research Question 2

The second research questions sought to analyze the communication between patients and nurses and the effects hospice nurses perceive compassion fatigue to have on those interactions. Within the end-of-life relationship, a hospice nurse has multiple roles; they are the caregiver, a guide, as well as an advocate. This results in patients, and family members, requiring a lot from their hospice nurse. While participants did not present these relational as a negative aspect of their job when first mentioning them, when asked about how they feel their stress and fatigue can affect their patients, hospice nurses did report the challenge associated with maintaining their multiple roles. Most participants identified their emotional support role was the first one to be eliminated when their stress

and fatigue was affecting them more than usual; this was exhibited through hospice nurses' explanation of how the more exhausted they feel, the more likely they are to be shorter with patients and to speed up their visits with patients as well (Keidel, 2002). Consequently, this often results in guilt within the hospice nurses due to them not feeling as if they have fully done their job; not being able to emotionally support their patients in the way they see fit not only causes guilt among themselves, it also can hinder hospice nurses' perception of their work environment (Wharton, 1999).

Hospice nurses who are primarily working in home settings often feel isolated from their other colleagues; while they value opportunities to unpack patient experiences with others, there is no set time for them to be in their office space. Overall, the sense of community between hospice nurses was overwhelmingly present, but only in situations where they were able to see and communicate with one another on a regular basis. Some hospice nurses make a point to go into the office in the morning, while others only go into the office when necessary; this results in a perception of being alone in a field where social support is crucial to maintaining mental wellness. This often results in negative feelings towards patients after difficult patient experiences, or after a patient death; many participants stressed the importance of not allowing the feelings from one patient interaction to the next patient visit. However, while this was an ideal way for hospice nurses to approach each patient visit, it is not realistic. Similar to the tension between closeness and distance discussed in the findings section, this is likely a result of socialization within the training and education process. Nurses feel it is their responsibility to make sure their feelings from one patient do not spill into another, but when a patient has just passed, or a nurse has recently left a patient whose pain they

struggled to get under control, they are not willing to acknowledge the residual feelings that may be present in their remaining patient visits. The stress and fatigue mentioned by participants and the aggravation of the stress and fatigue that occurs as the work week continues makes it exceptionally difficult for nurses to feel as if they are doing their jobs to the best of their ability. Nurses feel as if they are doing their best job when they are affording their patients as much time as possible, addressing all of their patients' needs and supporting family members. Therefore, when nurses experience compassion fatigue, they tend to be shorter with their patients, miss patient needs, as well as be shorter with families.

Practical Applications

The answers to the research questions revealed multiple areas for improvement not just regarding how the hospice field addresses compassion fatigue, but also what the health care field, in general, can do to contribute to the mitigation of compassion fatigue. Based on this thesis, there are a number of practical recommendations for hospice and health care providers.

First, socialization concerning surrounding hospice care should be more encouraging of the formation of personal bonds between hospice nurses, patients, and family members. Considering these connections are already occurring, encouraging them will allow for hospice nurses to remove the guilt associated with these connections as well as provide for a more collaborative environment between hospice nurses and patients. This socialization occurred for participants during nursing school; therefore, allowing for more time during rotations for education surrounding hospice and end-of-life care will allow for specialized education within this specific field. Doing so will also

remove the perceived dissonance hospice nurses experience between their feelings of connection between patients and their socialization to remain detached.

Second, while the stigma surrounding the use of opioids, narcotics, and other comfort medications is justifiable when considering the rate of addiction and overdose associated with such drugs; providers need to be cognoscente of the stigma when considering treatment plans for end-of-life patients. While the use of comfort drugs should be carefully considered when incorporated into a treatment plan that requires the patient to maintain their normal life, end-of-life care is solely focused on providing quality of life for patients. Therefore, while the common view surrounding drugs such as Morphine is that these drugs do more bad than good; hospice care is not focused on the long-term effects of medications. Therefore, when considering hospice as an option, doctors and medical directors should work to fully educate patients and families regarding the use of comfort drugs and the different role they play in traditional health care versus the role they play in end-of-life care. As a result, patients and family members will be more comfortable receiving the drugs best suited to their comfort, and the hospice nurse will feel more confident in their capacity to provide the patient with the best care possible.

A final recommendation is centered around encouraging health care providers to acknowledge the skill and effort required by hospice care; when non-hospice colleagues diminish the value of hospice care, hospice nurses themselves feel devalued. This can cause quick escalation of any underlying symptoms of compassion fatigue, resulting in a nurse leaving the hospice field. This lack of collaboration means doctors do not prioritize hospice patient medication alterations requested by nurses due to the already present

hierarchy between doctors and nurses this is further intensified by the lack of comprehension regarding the legitimacy of hospice nursing as a profession. Providing education regarding the importance and medical validity of hospice care will allow for other health care providers to appreciate the job done by their hospice nurse colleagues.

Limitations

Although the study worked to illustrate the ways in which hospice nurses report compassion fatigue effects their interactions with their patients, their colleagues, and themselves, there were some limitations to the study. First, the participants in this study were almost exclusively home hospice nurses; as a result, the issues presented by participants can be considered more representative of home hospice nurses, rather than hospital hospice care nurses. A larger sampling of hospice nurses within various environments including home hospice, home and hospital hospice, hospice facility, and nursing home hospice environments could provide a more expansive understanding of the consequences of compassion fatigue for hospice nurses from all hospice environments as well as provide the opportunity to compare the prevalence of compassion fatigue and various coping strategies for hospice nurses in multiple areas of hospice care delivery. Furthermore, there was a lack of regional diversity; all hospice nurses were from either southern Virginia or East Tennessee. Perspectives from a wider reach of regions within the United States would allow for more data and provide an opportunity to identify more commonalities. Finally, only eight interviews were conducted for this study, conducting more interviews would also allow for more data and insight.

Second, only the hospice nurse perspective was analyzed in this study. While the perspective of hospice nurses is crucial to understand the perceived effects of compassion

fatigue, including chaplain, social worker, or medical director perspectives could present a more thorough picture of the various effects compassion fatigue can have on interactions with patients, various hospice workers, and the overall organization as well as provide more insight into ways compassion fatigue can be mitigated. Additionally, including patient and family member perceptions could also provide a more exhaustive understanding of interactions affected by compassion fatigue.

Future Studies

Based on the findings of this study, there are multiple directions in which future studies can go. First, researchers should evaluate the perspectives of other hospice workers. Discovering their own beliefs and experiences with compassion fatigue will allow for a deeper understanding of the negative effects compassion fatigue can have between providers and patients as well as family members. With these perspectives, it would also be interesting to analyze current understandings of self-care and current strategies utilized to mitigate the toll of their job.

Second, this study could be performed a second time with a more representative sample of hospice nurses from more diverse hospice environments as well as more diverse regions. A more diverse sampling would specify more common occurrences surrounding compassion fatigue and provider-patient communication.

Finally, understanding the perceived barriers to facilitating end-of-life conversations with family members would be of great value. As previously discussed, hospice nurses are working towards helping patients accept their death, as well as helping family members to accept the death of their loved one. Therefore, researchers should

work towards determining these perceived barriers to productive end-of-life conversations in both patient-nurse settings as well as family member-nurse settings, so they may provide hospice organizations resources to better train hospice nurses towards facilitating these conversations in a way that allows them to feel confident in the multiple roles they play.

Appendix A: Interview Questions and Drawing Prompts

Drawing Questions/Prompts:

What are some emotional challenges you face in your daily job? What do those look like?

Draw how stress and fatigue affect your personal relationship with your job.

Draw how stress and fatigue affect your relationship with your patients.

Draw how you see stress and fatigue affect your colleagues.

Interview Questions:

Describe how you came to be involved in the hospice environment.

How long have you worked within the hospice environment? Describe a typical day in your job.

Describe some unique challenges you associate with being a hospice nurse.

Generally speaking, without revealing anything that would violate patients' privacy, describe some emotionally challenging experiences you've had with patients.

How do these challenges affect the stress and fatigue you experience in relation to your job?

How do you see stress and fatigue affecting your interactions with patients?

How does stress and fatigue affect your communication with your colleagues?

Describe an interaction with a colleague when you were feeling stressed. What kinds of things did you talk about?

How do you deal with work-related stress and fatigue? How would you describe your self-care routine (spiritual, emotional, physical, etc.)?

Is there anything else you think I should know that is important to my understanding of the effects stress and fatigue can have on hospice nurses and the care provided to patients?

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