ABSTRACT

HOW HOSPICE NURSES’ BELIEFS ABOUT DEATH AND DYING FRAME THEIR CAREGIVING

by Sarah Atala

In 2010, almost half (42%) of all deaths in the United States were under the care of a hospice program; 82.7% of those were patients 65 or older (Cirillo, 2012). Hospice care is implemented by an interdisciplinary team of care providers and poses biological, moral, spiritual, and religious considerations for both patients and care providers. Since nurses are the primary providers of hands-on hospice care, understanding their beliefs is important to understanding and improving hospice care. The purpose of this paper is to explore nurses’ beliefs about end of life issues and the way beliefs affect a nurse’s attitudes towards their care as well as their caregiving style. This study has three objectives: 1. Understand how hospice nurses describe their own beliefs about end of life. 2. Describe the relationship between a nurse’s beliefs and the daily tasks of caregiving for patients and their families. 3. Determine whether there is a difference in the attitudes of nurses between a for-profit and a not-for-profit hospice. This information will be valuable in improving hospice care by establishing a deeper understanding of nonphysical aspects of holistic care.
HOW HOSPICE NURSES’ BELIEFS ABOUT DEATH AND DYING FRAME THEIR CAREGIVING

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Background

Death and dying are concepts that are traditionally avoided in western cultures. Hospice care, which is associated with the dying process, has become an issue that is no longer taboo (Nakashima, 2007). As our aged population increases, new disease management techniques emerge, and cures to diseases are more aggressively pursued. However, the many medical triumphs we have seen have not reduced the number of individuals in hospice care. Hospice care is a care philosophy intended for terminally ill patients that is focused on comfort and quality of life as opposed to curative care. Hospice organizations can operate as either an in-patient facility, or an out-patient facility. Care can be delivered at a hospice facility, or in the patient’s home or long term care setting. The difference here is the setting in which the care is delivered, but the care philosophy is the same. Hospice delivers “comfort” care, rather than curative care in order to achieve a comfortable death. This care is delivered by a team of professionals who help the patient and their family through the end of life process. A healthcare executive turned long-term-care administrator, Anthony Cirillo (2012), tells us that as recently as 2010, almost half (42%) of all deaths in the United States occurred within the care of a hospice program; 82.7% of those were patients age 65 or older. The purpose of hospice care, also referred to as palliative care, is to reduce patient pain for the most comfortable death. This includes every sphere of the person’s life, including spiritual pain (Callahan, 2012).

A Taboo Comes to Light

Research on death and dying is a sensitive issue. Researcher Jacki Thomas (2004) offers the opinion that, in our culture, death is taboo because of a fear that if we talk about it, it is more likely to happen near or to us. The taboo is not restricted to talking about death. She offers a few examples of “death taboos” such as talking about funerals, and talking about the bodily deterioration that happens at the end of life. Whatever the reasons, talking about death is a generally uncomfortable topic. However in recent years we have seen a growing acceptance that death is a part of life, and being open to discussing and witnessing dying is not taboo. For individuals who are facing the end of life, this creates opportunities for acceptance and deeper relationships with care givers.

Nakashima (2007) attributes the transition from taboo to acceptance to the impact of the dying with dignity movement that started during the last quarter of the twentieth century. Dame
Cicely Sanders is the woman responsible for the movement; she faced the taboos of death head on saying, “You matter because you are you. You matter to the last moment of your life, and we will do all that we can to not only help you to die peacefully, but to live while you die” (Thomas, 2004). With this movement the general public is becoming more open to discussion of the experience of dying from a terminal illness. The sociologist, Lawton, already found that the public more readily accepted dying in the year 1998 than in decades before then, leading to a higher prevalence of people dying under the care of hospice, instead of hospitals. If we look today, this trend continues, as indicated by the statistics Cirillo (2012) found, “In 2010, an estimated 1.581 million patients received services from hospice.” To understand the dying at home trend that hospice promotes from a spiritual or beliefs-oriented viewpoint it is important to know about the roots of this philosophy.

**Roots**

Dame Cicely Saunders was a deeply spiritual and religious person, whose range of professional experiences equipped her for her most valuable contribution to the medical field: the hospice movement. She trained as a nurse, a medical social worker and finally as a physician (Cicely Saunders International). Dame Cicely not only founded a movement, she also “awakened the medical world to the spiritual needs of dying… patients” (Carroll, 2001, p. 82). Her legacy, an organization named Cicely Saunders International, records her involvement in the care of terminal patients as early as 1948. During this time, she also lectured widely on the subject, wrote many articles, and contributed to a great number of books. In 1967 her work came together in the founding of St. Christopher's Hospice, which was the first place where research and teaching hospice became linked with clinical care. St. Christopher’s pioneered the field of palliative medicine. Cicely Saunders International also records that Dame Cicely was involved with the creation of hospice teams around the world. She died on July 14, 2005 at St. Christopher's Hospice, the organization she had founded.

Hospice has evolved since Dame Saunders’ time, however the philosophy remains much the same. The hospice team is interdisciplinary and works closely with the patient and their family to holistically provide peace and comfort at the end of life. Every member of the team, as well as the patient’s family are important components to the care.

**Spirituality**
The nurse is a medical professional but is also traditionally viewed as the compassionate healthcare provider. So the question becomes, how do spiritually diverse hospice nurses care for spiritually diverse patients and families in the most holistic and optimal way? Despite the traditional perception of a nurses’ role, “only a few authors have recognized that the nurse's own spiritual and cultural beliefs may influence the way in which he/she approaches spiritual care” (Carroll, 2001, p. 82). Because spiritual beliefs are so deeply held, it becomes important for hospice workers to remain sensitive and aware of these issues. Manning (2012) tells us that spirituality has traditionally been neglected as a sphere of scientific study because it deals mostly with things that cannot be measured. Religion is defined by Edwards, Pang, Shiu, et al. (2010) as being characterized its boundaries, systems, and organizational structure. A religion is an institution with shared traditions, beliefs, and rituals. On the other hand, spirituality is harder to define. Spirituality is characterized by a difficulty in defining its boundaries. The word may be used by individuals who wish to move beyond institutional religion. The authors offer that spirituality can be defined as “a personal search for meaning and purpose in life, which may or may not be related to religion” (p. 753). Edwards, Pang, Shiu, et al. (2010) found, in their meta-analysis of the literature, that patients express a desire to feel accepted, loved and nurtured, but feel that spiritual terms to describe this need are too abstract or vague. Under this umbrella term of “spirituality,” for the sake of this study, are included several spheres such as relationship with self, relationship with nature or music, relationship with God or a higher power, and others. Researcher and Gerontologist, Lydia Manning (2012) posits that by virtue of being human, everyone has a capacity for spirituality. In late life, spirituality is a search for meaning in life, responding to that meaning, and developing a relationship with God or others. For the purpose of this study religion, spirituality, values, philosophies and any other form of belief will be explored. Different individuals have diverse views regarding these sensitive topics. This study, in attempt to be accessible to all participants, and to avoid excluding any views, will use whatever words are comfortable for the participants. The distinctions made previously are included only to give a deeper understanding of this broad issue.

Dr. Puchalski (2008) suggests that there is a growing focus on training health professionals to care for their patients’ spiritual needs: “Today, the majority of medical schools teach courses on spirituality and health because of the recognition that spirituality, defined broadly as that part of people that seeks meaning, is essential to healthcare, to the patients’
stories, and to the impact on healthcare decision making and coping.” Ardelt, Ai, & Eichenberger (2008) tell us that the search for meaning in times of trial is common. This need of the patients’ is being identified and met by the medical community. Meaning-making, a concept described by Victor Frankl in 1963, is an important psychological undertaking to individuals who are dealing with the emotional aftermath of their diagnosis (Ardelt, Ai, & Eichenberger, 2008). This process is attributed to the tension between an acceptance of the end of life, and the human instinct to preserve life. The response to this internal conflict is to search for or create meaning. Author for Generations, R. Atchley (2008) defines meaning as “the need for sense—an understanding of how things happen and why—significance—the order of things in a system of values—and purpose—the clear set of goals.” It is a way to orient oneself to the present and the future. The desire for predictability is satisfied by adhering to a belief system with which to face the future (Ardelt, Ai, & Eichenberger, 2008). Spirituality and meaning-making are closely related issues for some people and the end of life is a time where many people begin, or continue, to search for meaning.

The need to be sustained, not only physically, but in nonphysical spheres stems from what Frankl (1984) and the philosopher Martin Heidegger (1962) termed "a constant lack of totality." Carroll (2001) explains to her readers that a “constant lack of totality” is the lived experience of planning for and thinking about the future, the portion of life that has yet to be lived. This notion is tied to a constant experience of unfinished business which is only “finished” in death. A constant lack of totality is an abstract psychological situation which, at the end of life, may need to be sorted through with a chaplain, whether the patients belong to an organized religion or not. When the end becomes an imminent reality, the patient’s constant lack of totality is compromised and they experience emotional and spiritual distress. Nakashima (2007) found that in old age, when this type of concern becomes relevant, religiousness and spirituality take on increasing importance. Carrol (2001) writes that an understanding of spirituality as pertaining to medical care is both widely accepted, and still in need of exploration within the many disciplines that are relevant to this issue.

Nurses are an integral component of a hospice team and are usually the primary caretaker concerned with biological functions. Social workers, chaplains, grief counselors, and other team members expressly deal with the emotional and spiritual side of end-of-life, however, a holistic approach requires that all members of the team support the patient in every way. The role of each
member of the team is not a stark boundary. The team works together to serve the patient as best they can, and all help each other. Each member of the team serves as eyes and ears for the rest of the team while with the patient and family. “Several authors have suggested that, in order to recognize the spiritual needs of others, nurses must first explore their own spirituality,” (Carroll, 2001). While there have been significant medical and social triumphs in hospice, like a better understanding of the biological processes and an alleviation of the shame that traditionally surrounds death, there is still an opportunity to learn about the spiritual aspect of a hospice nurse’s job. In Carroll’s study (2001), the nurses identified spirituality as being unique and individual. Nurses “felt that spirituality was personal, while being part of the “whole being.’ As if to say that this private part of a person cannot be separated from the parts of them that are cared for by medical professionals. Nurses in Carroll’s study also expressed that “spirituality embraces our relationships with others and the world around us,” and therefore cannot be completely divorced from patient-nurse relationships.

Nurse-Patient Relationship

The nurse’s traditional role is that of both medical expert, and compassionate caretaker. While the chaplain or clergy are expressly responsible for the spiritual care of the patient, these roles are less stark in practice. The nurse, as a caregiver can also be called upon at times to provide spiritual or emotional support. Sometimes the nurse is the person who observes a patients’ spiritual distress first and is the one to inform the chaplain or clergy. In the intimate experience of end of life, the nurse can become a friend, an ally, an advocate, or an enemy. Nyatanga (2012) discusses some of the taboos that nurses face when working in palliative care. There is a rapport that must be built between the patient and the nurse before they can ever discuss dying, bowel movements, or sex. There is beginning to be an openness in the medical world to discuss death and dying during the end of life, and even before a terminal diagnosis. Mok and Pui Chi (2004) found that the nurses and patients in their study derived meaning and closeness out of the patient’s suffering as coping mechanisms. The nurses’ proximity to suffering cause them to search for meaning alongside their patient. Four important processes were discovered in the relationship between hospice nurses and their patients. The first of these processes was an encounter that sought to reduce suffering and maximize comfort. The nurses found satisfaction in their ability to comfort their patients. The second process was forming a relationship of trust and connectedness. The patients valued feeling like their needs were
anticipated and met by the nurse care giver. The third important process was revitalizing energy. The nurse was seen as a source of strength and encouragement, someone who could ‘refuel’ the patient’s sense of acceptance. The fourth process was enrichment. The nurses were expected to provide enriching and encouraging experiences for their patients by getting to know the patient personally and addressing their unique needs. These processes worked best when there was openness and communication between nurses and patients. This openness to discussion and mutual search for meaning is also important in dealing with families.

_Caring for Families_

End of life is rarely a phase of life that is experienced individually. Death effects more than just the person who is dying. The hospice experience usually involves the family and friends of the patient. Given the influence the hospice nurse has on a person’s death, he or she will affect the experiences of the family that their patient leaves behind. Family members may benefit from knowing that their loved one has had a good death. The dying with dignity movement has brought to light that patients and families believe that the absence of physical pain alone does not constitute a good death. There are non-biological components to a good death, and the expectation has become that physical, emotional, spiritual, and psychological pain must be treated in both the patient and their family. The involvement of family in hospice care is very important and comes with both rewards and obstacles. Families sometimes have complicated histories, divergent goals, or emotional barriers that can muddle the nurses’ job. Hudson, et al. (2004) describe some of the barriers that may disrupt communication between family, care recipient, and health professionals. Sometimes there is unfinished business or unspoken resentment built up in family situations. Sometimes the needs of the family and patient impede each other. Trust issues, cognitive impairment, and grief can also cause misunderstandings between families, patients, and medical professionals.

Chan and Chan (2013) found three aspects of care which bereaved families and their dying loved ones attributed to their feelings of being supported. These aspects are to: be informed, supported emotionally above and beyond medical care, and spend quality time with the family. Nurses, as members of the hospice team, are in a unique position to facilitate these three needs. In this same study, nurses expressed a belief that good care involved providing the family, as well as the patient, with up-to-date information and being open about the patient’s condition. However, nurses expressed that providing bereavement care to families is emotionally
draining (Chan & Chan, 2013). This emotional drain is caused by the dynamic of needing to stay calm for the sake of the family, while also feeling grief over the patient’s death. Nurses are expected to facilitate grieving without properly taking time to grieve themselves (Chan & Chan, 2013). Researchers, Chan and Chan, suggest that nurses have to place the concerns of the bereaved family members as the first priority when providing bereavement care, so as to prepare them to accept the loss and to cope with the grief. Nurses must support patients and families, regardless of the difficult circumstances they may bring. That is why the second objective of this study is to learn how nurses navigate their caregiving role between their patients and their patient’s family.

**Good Death**

The hospice movement has continued to grow since the passing of Dame Cicely Saunders. Today, in palliative care comfort is the top priority, especially at the end of life. Hospice is usually administered to a patient by a team of professionals. Nurses, as part of a hospice team, are the primary providers of hands-on palliative care. They work with patients and families to achieve a “good death,” which is described by Steinhauser’s (2000) participants as a death that is pain free, with decision making on the part of the patient, and an acceptance of the impending death, as well as care for the patient psychologically, emotionally, and spiritually.

Thomas (2004) reports that patients at a hospice day center (an adult day care that administered hospice during business hours) commonly experienced depression, isolation, and guilt. These are all feelings that the nurse, as a caregiver, will face with their patient. Thomas (2004) suggests humor as a good remedy for fear and psychological pain. Lawton (1998) found that the physical deterioration, the process of a body becoming ‘unbounded’ as it approached death, presented a large obstacle between patients and formal or informal caregivers. Lawton saw that caregivers sometimes exhibited a negative attitude towards patients who were experiencing this ‘unbounded’ body transition. The feelings of shame and depression that threaten a dying patient set them up to experience a bad death. As a care provider with hospice, the nurse plays a pivotal role in determining whether the patient experiences a good or bad death.

Hospice nurses are the primary biological caregivers in hospice care. The traditional role of a nurse is also to be the face of compassion, a gentle touch. The hospice movement, from its very beginnings, has sought to comfort individuals holistically, alleviating spiritual pain, as well, as biological pain. Because ideas of spirituality are so personal and hard to measure, the hospice
nurse carries the burden to understand their own beliefs, while also caring for patients and families of diverse belief systems. Hospice nurses work alongside their patients to find meaning in life, accept the terminal nature of their illness, and add meaning to the limited time their patients have left. This study seeks to explore the way nurses view their own beliefs both personally and in their work environment via a grounded theory approach.

**Research Objectives**

This study used a grounded theory approach to explore the ties between hospice nursing and individuals’ beliefs. The driving objective of this study is to explore the following:

1. *Understand how hospice nurses describe their own beliefs about end of life.*

   In this study, beliefs are conceptualized as religious, spiritual, philosophical, or emotional principles and convictions. Nurses were encouraged to use words that felt natural to them. If they were religious, they were encouraged to talk about religion. If they were more spiritual, they were encouraged to speak in those terms. End of life, a topic which is still partially shrouded in taboo and mystery, compels people of different beliefs and cultures to ask questions and develop answers. What happens after we die, how we treat a deceased body, and appropriate ways to grieve, are deeply important and sensitive to some people. This question seeks to get hospice nurses to address and describe their beliefs related to end of life.

2. *Describe the relationship between a nurse’s beliefs and caregiving.*

   This study question is meant to deepen our understanding of the experiences of hospice nurses and how their own deeply held spiritual beliefs inform, or are informed by their work as care givers in hospice. As a professional who witnesses the decline and death of most of their patients, a nurse is often confronted by both, their own beliefs about death, and their patients’ beliefs. The nurses also encounter and interpret their observations of patient decline and death. This question seeks to get hospice nurses to address how they navigate the similarities and differences they share with their patients, in terms of beliefs.

3. *Determine whether there is a difference in the attitudes of nurses between a for-profit and a not-for-profit hospice.*
Because the business model between a for-profit and a not-for-profit are different, this study aims to find if these differences filter down to the hands-on care givers. This question aims to draw out whether the difference in business model causes a difference in the experience or perspective of employees of hospice organizations. This study is not primarily comparative, but during analysis this researcher will remain mindful of the different business models.

Methods

Grounded theory is based in symbolic interactionism and the assumption that people are self-aware in such a way that an individual can describe their self to a researcher to create data (Heath & Cowley, 2004). Based on these assumptions, the data were collected via in-depth interviews, either face-to-face or over the phone. All interviews were audio-recorded. Face-to-face interviews were preferred over phone interviews because of the greater availability of social cues to the interviewer. Social cues, such as voice intonation and body language, can give the interviewer a context that can be regarded alongside the verbal answer to a question (Opdenakker, 2006). An example of this is if the interviewee uses sarcasm or irony, it was conveyed in both their vocal inflection and facial expression. Telephone interviews were acceptable because they still allow for the interviewer to pick up on vocal cues and timing. It was more important that the interviewee be heard than seen, but both were desirable.

Interviews

In the interviews, the participants—hospice nurses—were asked to describe their beliefs about the end of life. The questions were open ended to prompt long, narrative answers. The interviewer had a list of questions prepared before the interview but the interviewer was free to follow a line of questioning that was relevant to draw out as much information as possible. Interviewers were allowed to know the predetermined questions and have a hard copy of them to use during the interview if they desired, however the bulk of the interviews were conversational and allowed the interviewee to decide the direction of the conversation. The interviewee was only redirected when the conversation began to stray too far from the research question. Interviews were transcribed immediately and all identifying information was removed for confidentiality. Names of non-nurses and places, such as family members, co-workers, and towns, were reduced to the first letter, nurses were given pseudonyms, and all identifying years (such as graduations or job transitions) or titles were removed. Coding took place in the same months as interviews were being conducted so that each interview was directed and informed by
the codes found in previous interviews. The researcher was careful to avoid what Heath & Cowley (2004) refer to as forcing the data. The interviewer should be mindful not to “lead” the interviewee into certain topics of discussion for the sole purpose of validating a specific code. The interviewees were encouraged to tell stories that come naturally to their mind. The codes that were generated were kept if they were verified by multiple respondents. Codes were refitted as needed to ensure authenticity.

Interviews began with the interviewer asking the participant to describe their life story; the participant was then asked probing questions about how they began working with hospice. Once that trail of questioning was exhausted the interviewer asked about the nurses’ beliefs about death and dying and the delivery of care. There were questions about what a ‘good death’ looks like and what the nurse looks for when dealing with the grief of the family.

Interviews lasted sixty to ninety minutes, due to the time constraints that are common to workers in hospice, as it is a ‘round-the-clock’ job. The nurses were recruited from two different environments: a for-profit hospice, and a not-for-profit hospice. These hospices were from the same midwestern state. Transcripts were coded with the for-profit/not-for-profit dynamic in mind to see if any differences manifested, however this was not a comparative study. During coding, the for-profit nurses were treated as a group and the not-for-profit nurses were treated as another group to see if the groups differentiated themselves in any way. They did not. Nurses were asked to volunteer their time for this interview. The interviews were conducted in a private room at their place of work, or a public, “neutral” place that provided some privacy such as a coffee shop. The locations were determined based on where was most convenient for the participant.

All data, including audio recordings, transcripts, analysis and excerpts from interviews were checked for accuracy. Participants were identified only by their pseudonym; identifying information was eliminated. All study information was kept on a USB drive that was kept in a locked drawer to assure confidentiality. Paper copies of transcripts, consent forms, and interview materials were kept in the same locked drawer. Only the Primary Investigator had a key to this drawer. Consent forms were given to one employee from each organization to be circulated among the nurses. Interested employees contacted the interviewer to schedule interviews.

Analysis

The data were analyzed using open coding to identify the similarities and differences among participants and between the two organizations. The primary investigator also conducted
thematic analysis to identify patterns among participants and establish the common themes. Once themes were identified, the researcher did member checking by sending results to the site coordinators from the two hospice organizations to be distributed to the participants for feedback. The results were distributed via the same employees who distributed the consent forms. Feedback was sent from nurses to the researcher directly, not via the same employee. Feedback affirmed that the researcher had accurately portrayed the ideas of the respondents. Saturation was reached once new codes stopped emerging in the data. Qualitative researcher, Janice Morse (2000) tells us that sample size can be determined by the quality of the data obtained in each interview. A long interview may yield very little data while a short interview may prove to be very rich. Therefore, this researcher did not choose a number of participants, rather the study progressed once good quality themes begin to emerge. The researcher recruited the same number of nurses from the second organization. The twelve nurses ranged in ages between early thirties and late fifties. All of the participants had a minimum of one year of experience working in hospice, although some had a few decades of experience in hospice. Table 1 lists the participants by pseudonym, age range, and organization. All participants are referred to as female in order to protect their confidentiality. Nursing is a predominantly female field which makes any males more easily identifiable. Ages are obscure for the same reason.

The study duration was sixteen months. The first four months were spent gaining permission and access to interviews. The next eight months were spent interviewing and coding. During this time, once saturation was achieved for the for-profit hospice, the not-for-profit organization was chosen and interviewing and coding continued. In the last four months the primary investigator developed themes and did member-checking, as well as wrote up the results. The study lasted from December to March of the next year.

Results
This analysis seeks to understand three broad issues: How nurses describe their own beliefs about end of life, how they describe the relationship between a nurse’s beliefs and the daily tasks of caregiving for the patient and their family, and whether there is a difference in the attitudes of nurses between a for-profit and a not-for-profit environment. Several themes emerged within these three areas of inquiry. The beliefs given to them by their families in childhood, as well as the experiences of putting loved ones through hospice seemed to be important to the journeys of the interviewees. Experiences in different care settings and the
diversity of patients were contributory to the nurses’ beliefs about caregiving. The differences between for-profit and not-for-profit organizations did not appear to be as important as other topics to the participants. None of them expressed a conscious preference for either business-model, or seemed to seek employment based on this distinction. The following sections present the subjects that the nurses addressed in their interviews.

*Own beliefs*

Every interview began with the nurses being asked to describe who they are and how they came to be hospice nurses. All of the nurses stated that they were raised in a Christian denomination. One specifically stated that her father had converted to a non-Christian religion and that had been a significant event for her. She explained,

> It's difficult because my father is [new religion]. So thinking about possibly not seeing him [her father] in Heaven or having him walking me over…into God's…it's hard.

Many of the nurses, like this one, brought up their families’ beliefs in the interviews. She felt that this event had shaped her beliefs about the afterlife. The nurses own beliefs, and those of their families, suggested that there was a part of a person that lived on after the body died. In the above quote, it was the part that went to heaven. In other cases, the person lived on in other ways. It was also common that they would talk about the experience of putting a loved one through hospice. These memories were recalled as positive, in terms of hospice being supportive. These memories were sometimes cited as important to the decision to work for hospice. For example, Tracy, a fifty-something-year-old participant, told a story about using the hospice she worked for when her husband passed away and the difference it made to be on the receiving end of hospice. She said:

> When my own husband was dying and had hospice, I was overwhelmed with the kindness. It was my hospice that took care of him, and I knew how great it was. I knew how these nurses were wonderful. I knew how the chaplain was wonderful, but when you're on the receiving end, it is an entirely different experience and every day I was overwhelmed by the kindness that these people showed to him and showed to me.

Her comments, and those by the other respondents, suggest that the nurses believed in the hospice philosophy, and perhaps even their particular organization’s style, enough to use it for their loved ones. This type of gratitude was expressed by each nurse who had hospice for a loved
one. Watching a loved one die is always difficult and the hospice team holds a delicate place in the experience.

Sam explained that the dying process is slower than most families expect it to be. She liked to explain to families that ‘crossing over’ is a slow process in the following way.

I share with them a story about having a foot on the land and the sea. One foot is on the land of Earth, one foot is on the sea of life and they're stepping out, testing the waters in the sea of life to see if that's something that they want to continue experiencing…And then eventually that foot that's on the land is going to step on over and as they step on over that's when they're going to take their last breath.

Sam said that this story both comforted families and accurately depicted what she believed. Dying doesn’t happen in a moment, it is a slow decline, and Sam would provide this explanation to families to assist them with their feelings of helplessness and confusion.

Overall, the participants related their belief in the hospice philosophy to their experiences with losing loved ones and the way they have helped others who are losing loved ones. Feelings of loss and uncertainty were reconciled by a belief that there is a part of each patient that lives on in some way. The nurses are primarily responsible for the biological aspects of care, the parts of a person that deteriorate. The interviewees expressed that a large portion of their work involved teaching families and patients about the biological process of dying.

Nurses are primarily trained to take care of a person’s biology. This means they can give medication, clean wounds, and other types of care related to bodily health. A body near the end of life develops different needs and processes than a non-terminal body. The nurses usually described educating patients about these biological changes as a big part of their day-to-day job. Mary, a forty-something-year-old nurse felt that the average family didn’t know what to expect at the time of death. She said,

I think a lot of the family's expectations might be formed by what they've seen on TV or maybe what they've experienced with somebody else and so, I mean that can make your expectations high or low. Maybe if they saw somebody have a terrible death, you know, they think that this is going to be terrible, too. Or they see something just dreamy and, oh, the person is speaking to them, but as they're taking their last breath. You know that's not usually realistic.

The nurses described the dying process as a sort of ‘shutting down’ of the biological process, and the release of the non-biological part which lives on after death. One of the nurses said that in some cases, the spirit may leave the body early, leaving behind a machine that is just going through the motions. Overall, the biological process was viewed as secondary to the
spiritual process of dying. The biological process seemed to be the hardest to watch and the most troubling for families. Sam said,

When they [the patients] become non-responsive then families will ask me ‘What's going on? Why is this happening?’ And instead of going into medical terms, because a lot of our families don't understand the medical terms, and they ask the question as if it should be a medical rationale but I don't give that.

Sam felt it was more important to educate the families about the spiritual journey of dying, not the biological component. The nurses felt that they needed to be in a position to educate patients about the biological process of dying, but also to be supportive in a spiritual sense.

Many of the nurses viewed a large part of their job to be equipping families with knowledge of what to expect to see and feel when their loved one died. Because of the taboo surrounding death, many people either had wrong expectations, or had no idea what to expect. As professionals who deal with death day-in and day-out, the nurses viewed themselves as experts on what to expect at the time of death, and felt it was their duty to prepare their patients’ families. Many of the nurses echoed the belief, formed by years of observation, that dying was a journey that did not happen in an instant. Each death was viewed as unique to the individual.

Jane said,

I'm a firm believer…there's certain kinds of deaths. There's like sudden death and then there's like a slower kind of death where they go through a state of responsive…like they're responsive, then they're non-responsive, then they're minimally responsive and then eventually they pass away. I'm a firm believer that somewhere in that non-responsiveness, the soul leaves the body. You can see it. I…you can tell when somebody is there and when they're not and when the body just seems to be a machine, going through the motions. So, I believe at some point, something happens there and the soul leaves the body. Where it goes? I don't know. I do believe that if it's heaven, then there are people there waiting for you.

What she suggests is that death is a very individual and unique experience. No two people die in the same time period, or same type of decline, but that there are also universalities that families can be prepared for, like a time of unresponsiveness or a loss of appetite. Jane also had a belief about the afterlife which she liked to share with families about people waiting to receive the deceased into heaven.

There were two different ways that the nurses formed their beliefs about the afterlife: formal doctrine, and observation. These two things are not a dichotomy, but rather a continuum on which the nurses fell on either side. Their beliefs in the afterlife were either formed primarily
on religious doctrine, or *primarily* on personal observation. Some of the nurses held to a view of the afterlife that was in keeping with their religion for example, one interviewee said,

> Well, just looking at what the Bible teaches, this is my belief and it comes from the Bible. When Jesus comes back, returns, Heaven and Hell will be ready, but until that time, if somebody dies and are going to Heaven, they go to a place called ‘Paradise’, and if they die and are going to Hell, which I know is not popular to a lot of people because they don't like to think about going to Hell, but according to the Bible, they do. Unfortunately, if someone is going to Hell, they go to a place called ‘Hades’. That's my belief.

Relying on a formal doctrine of the afterlife was usually supplemented with personal observations that confirmed their beliefs. Nurses talked about patients who had seen angels, deceased loved ones, or even flames which proved, to the nurses, that parts of a person lived on after biological death. Other nurses had developed a view which was an intersection of their religion and their observations with hospice. One nurse explained,

> It depends on their faith. I've had patients that are Jewish—I had to cover mirrors...and Jewish and Islam or Muslim people fight over a holy land but they're very similar in their deaths. They don't believe in embalming. You have to get them into the ground quickly. Don't desecrate your body with tattoos and things like that. They're very similar in their dying processes. So for me, I believe people go to Heaven or...well, that's where I plan on going but other people...it just depends on where they are in their faith and hopefully reconciling if they don't have a faith system. And if they don't, that's okay too. I don't know where they go. That's an unknown. So hopefully God embraces everyone at the time of death. It's hopeful.

This belief that everyone is welcomed into the afterlife that they personally ascribe to seemed to stem from an observation of the diversity of end of life practices with which a hospice nurse experiences. Each religion and culture has at least some rules about end of life, such as proper method of burial, the proper treatment of a dead body, or the proper way to grieve. Catering to these diverse needs, which are intimately bound to the belief systems they come from, lead some nurses to hold the view that every practice and belief holds value and truth. Sam said,

> After they finish their journey here. They begin a new journey; may it be however they—that person as an individual believes with their faith. That's the foremost when I'm with one of my patients. When I'm with my family it's all based on the religion we were raised. So, you know, you have to keep that difference. For the most part everybody has some form of religion. For the most part most people believe in there is a Heaven and an afterlife but the way they believe about it you have to respect that as the nurse for that individual.
The most important thing seemed to be respect for differences. The nurses were open about their own beliefs but were very insistent that respect for differences was their top priority.

Only one nurse expressed a belief in reincarnation as opposed to a final repose. This belief was based on personal observation. She said,

That's how I've developed that [belief in reincarnation]. [It’s] More than what somebody's told me, it's like… I guess, just through my own experience, especially … we've lived more lives than…you know, I guess if you want to call it reincarnation. I just think it's…it doesn't make sense just to die and nothing happens. Yeah, so it's just been more of a journey with me and seeing what I feel inside and what makes sense to me.

This nurse, Rose, a forty-something-year-old nurse, spent a good portion of her interview talking about her spiritual journey. She founded all her beliefs on observation and what felt right in her heart. The ideas she expressed demonstrated how difficult it is to measure concepts of spirituality, but how deeply our beliefs affect us. The nurses’ journeys suggested that there is a cycle of observing a death through one’s own spiritual lens, then informing their beliefs by their observation, then letting subsequent observations be influenced by those personal beliefs. This cycle led the nurses to a sense of compassion for both the biological aspects of their patients, but also their relational and spiritual needs.

The participants shared several of their observations regarding what they’ve seen happen during a death and what they believe happens after. All but one nurse had witnessed patients dying ‘on their own terms.’ The patient appears to hold out to die under a specific circumstance. This idea was usually illustrated by a common anecdote among the interviewees. The example was of a hypothetical patient who would insist on dying with no one watching. This was because of a desire for dignity, or a desire to protect their loved ones from trauma. For whatever reason, the patient’s terms were that they wanted to die alone. The patient’s family would be perpetually present and vigilant, telling the patient it was okay to die. Then a night would come when the patient only had one or two ‘vigil’ visitors. The visitors would step out to make a call or use the restroom. The patient died in the five minutes that everyone stepped out. Variations on this story were told to illustrate how a hospice patient sometimes appears to die on their own terms. Another form of ‘dying on their own terms’ was to appear to halt the decline towards death and hold out for a ‘last time.’ By this, I mean, that patients would appear to hold on until they got to say good bye to a specific family member, or have one last steak diner, or hear their spouse give
them permission to die. The patients would not die until they got their ‘last time,’ and then die within minutes or hours.

Mandy was the only nurse to vocally disagree with this common belief, saying,

And one of the big things I think a lot of people tell families is that they have control over when they're going to die. That doesn't fit with my faith belief. Because I believe God is in control and we aren't. We would either live forever because we don't want to die, or, a lot of people want to get it over with, quickly.

Mandy’s belief that God is in control was proof enough, to her, that these ‘hold-outs’ were due to God’s intervention, not the patient’s force of will. This is yet another example of how beliefs and observations inform one another.

A more common event at the time of death was what I’ve termed ‘escorts,’ appearing to the patients. Escorts are otherworldly beings, deceased persons, or physical experiences that only the patients perceive. Some observers might call these events hallucinations, however the nurses who had patients experience this did not. Before their death, a patient would tell the nurse that a deceased family member, an angel, or someone else came to see them. Angie told me,

“I've seen people say, you know, ‘My mom came back. My dad came back. My whoever came back. They're here.’”

Some of these ‘escorts’ were not pleasant, however. One nurse, Lisa, told the interviewer about a patient who saw and felt flames at the foot of his bed and believed it was his transition to the after-life. She told me that this patient was described by his family as heard to deal with, and the story about the flames was interpreted to mean that he was being punished.

Some of the interviewees believed that if a caregiver does not understand their own beliefs, they cannot care emotionally for their patients. This belief was more common among the not-for-profit nurses, but was present throughout both organizations.

Beliefs in Caregiving

In the first interview a theme emerged which would be echoed in all twelve interviews. The interviewee, Sam, called it “burden verses benefit.” The belief in burden verses benefit always came down to one priority: patient comfort. The nurses explained that some medical procedures prolong life while inflicting pain, or causing emotional distress. One example of this is a feeding tube. A feeding tube will keep a patient nourished, but for a patient whose body is rejecting food and shutting down, it will cause discomfort and stress. Burden verses benefit is the
practice of considering each new medication and procedure for comfort purposes, not curative purposes. Any procedure that would cause discomfort was against the hospice philosophy. The benefits of a feeding tube sometimes do not outweigh the burden it would put on the patient.

All the participants mentioned, in one way or another, their commitment to making sure treatment never causes their patient discomfort. Sam explained,

That's where I run into problems with some facilities because I question ‘Where's the comfort in this?’ The burden versus the benefit. Why put a person through speech therapy to try to find a best diet for them when everybody understands the disease process of Alzheimer's; the person is declining. Why are we going to burden that patient and make them feel like they need to perform and give them anxieties and then they become agitated and frustrated? Why? Where's the benefit in this for the patient? … Quit putting the burden on the patient for performing.

Many of the nurses repeated this belief that care should never impede comfort. All of the testimonies suggested that the nurse’s highest goal was patient comfort. They explained that if there were non-aggressive alternatives to hospitalization or surgery, those were preferable to allow the patient dignity and comfort. This sentiment was coupled with a desire to see patients in their own homes, surrounded by family and pets, and comfortable. This was considered a “good death”

Sam, Angie, and Tracy stated that their belief in burden versus benefit stemmed from their experiences working in an Intensive Care Unit or Emergency Room (ICU/ER). They felt that the aggressive, fast-paced, approach to care in an ICU sometimes overlooked, and sometimes disregarded, the patient’s wishes and dignity. Tracy attributed this to the attitude that prevails in the medical field that death is to be avoided at all costs. She told this story as an example,

This man, he died a slow miserable death. He never left the hospital. He had multiple infections and because he was – from the doctor's side – they kept saying, ‘He's only 35 or 34,’ and I kept thinking, ‘Does that mean you can't die? People that are 34 die. People that are 12 die.’ And has he not given it his best shot here? And should he not be allowed to die with dignity and maybe in his home?

The aggressive treatments administered in the ICU sometimes caused the patient to experience more discomfort, and sometimes left them with permanent infirmities, such as broken bones or dependence on medical equipment. In Tracy’s example, the 34 year old patient in the ICU suffered tremendously. She described,
His wife kept saying, ‘Oh, we’ve got to keep doing this [aggressive treatment].’ … He had a huge wound in his gut that wasn’t healing because of all the steroid use… they gave him a glass of grape juice. We used to do that to see if there were [holes] in his stomach… And he drank this bit of grape juice and when you looked down into his stomach, it looked like a sieve. All this grape juice was coming out of all these holes. At that point the docs said, ‘All we can do is remove his stomach. Because it’s just full of holes and it’s not going to heal.’ And his wife said … ‘We have to do it because it’s going to save his life.’ And it wasn’t going to save his life. This man was going to die and he was going to die a slow, miserable death, being chopped apart little by little over time.

Stories like this one, where patients were treated aggressively at the expense of their comfort and dignity, were common among the nurses who had worked in an ICU. They admitted that there was a thrill in rescuing people, but in the end, the patients’ discomfort was always too troubling to continue working in this setting. A few nurses named ‘burden verses benefit’ as their reason for leaving the ICU and going into hospice.

One of the unique attributes of working in hospice is the opportunity to build deeper relationships with patients. This is not possible in a setting like an ICU. One of the benefits of good hospice care is emotional and spiritual support. Each nurse had stories to share about patients and families that were religiously different from themselves. Having many experiences building deep relationships with diverse caseloads seemed to be valuable to the interviewees. Tracy said,

I think what I learned over time is, a Muslim is not a Muslim is not a Muslim and a Jew is not a Jew is not a Jew. You really need to find out from each one what is their expectation and what is it that they want. … I think one of the things I learned was asking the family, ‘What is your expectation at the time of death? What would you want me to do or not do? Who do you want me to call or not call?’ I found that to be the best way to address those needs.

Most of the nurses agreed with this belief that the patient’s spiritual needs had to be assessed on a case-by-case basis. The nurses seemed to have a desire to really understand their patient’s spiritual needs and be able to cater to them. Kathy, a nurse with the not-for-profit hospice, recalled an instance where a patient’s beliefs presented a challenge to her care,

I do remember a story about… I think they were Hindu, Islamic, maybe. It was where it was a young woman in her forties. We weren’t allowed to talk to her. We had to talk to the husband about everything. He was okay with a woman coming in to take care of his wife, but when it came to making decisions it had to be him and man talking… He would speak to me, but when it came to making major decisions or… I could tell him what my assessment was for his wife, but … when he got his wife on service, no woman could go out and talk to him about that. It
had to be a man, because that was the big thing…. I think that’s just their belief and how their culture was, and I respected that.

Kathy said that while this experience, while challenging, gave her an appreciation for the differences some of her patients have and affirmed to her the importance of respect.

Kathy’s approach was to embrace the differences. Among all the interviewees, when it came to navigating differences, there were a few different approaches to this that came about. Some of the nurses would keep their own opinions entirely to themselves, no matter what, while others would try to create a connection via the sameness or differences in their beliefs. Angie described her feelings on this issue in this way,

Well, I think that sometimes your attitudes can be different if you're a believer versus a non-believer. And most likely … I'm not saying you can't be caring or something like that. But maybe you understand more especially if you're going into a home where they are religious, they are Christian. I think it's very important because a lot of people are … and if you're not a believer and you're going in, you really don't connect with them at all. That would probably make it hard and so you just have to be careful what you say, I guess.

Angie felt that respect could be communicated by being careful what you say. She felt that shared beliefs between patients and nurses could contribute to a closer relationship. This idea was communicated more strongly among the nurses from the not-for-profit hospice, although not exclusively.

For-Profit v. Not-For-Profit

Initially, this study sought to compare views between nurses from a for-profit-hospice, and a not-for-profit hospice. As the interviews progressed it became clear to the researcher that this difference was not something that the participants thought about or were interested in talking about. In analysis, there seemed to be few important differences between the verbiage, outlooks, and experiences of the nurses from a for-profit hospice organization and a not-for-profit. Because this is not a primarily comparative study, any differences may have gone unobserved.

The only difference observed was a slightly heightened willingness, among not-for-profit nurses, to talk about the importance of being able to understand their own beliefs. The for-profit nurses addressed this topic as well, but the depth of the discussion was greater among the second set of nurses. Suzan a forty-something-year-old nurse from a not-for-profit hospice, said,

People that are Christians and have that faith …it’s much easier for me as a Christian Hospice nurse, much easier to comfort them. But, the people that are flat out atheists, it’s hard for me to comfort them, spiritually, emotionally… I had an
atheist patient once a couple of years ago that I tried to talk to about becoming a Christian and she was not interested, very polite about it and I, of course, was very polite about it, but I saw her a few days before she died … and I said, ‘Are you still an atheist?’ She nodded ‘yes’ and I said, ‘Are you sure you want to stay an atheist?’ and she nodded her head ‘Yes’. There are many people… I deal with more people who are Christians than the opposite because it seems like … Most people have had some sort of religious feelings by then[at end of life] knowing that if they haven’t shaped up by then, they’re going to shape up now.

For the most part, a majority of the patients described did hold to some form of religion, and the nurses were trained and prepared to interact with diverse patients. The not-for-profit nurses spoke more about how it was easier to provide spiritual care to patients who were similar to them in their beliefs.

Concluding Results

The driving force of this study was to explore three objectives. The first was how nurses describe their own beliefs about end of life. How they describe the relationship between a nurse’s beliefs and the daily tasks of caregiving for the patient and their family was the second area of inquiry. The third research question was whether there is a difference in the attitudes of nurses between a for-profit and a not-for-profit environment. The nurses shared many insights into these objectives. They shared their experiences with spirituality and religion in their childhoods, the deaths of loved ones, and in their work. They described the spiritual components of caring for diverse patients and families. In the end, the comparison between not-for-profit and for-profit organizations proved to be unimportant to the participants.

Discussion

The themes that emerged during analysis give us insight into our study objectives. Nurses discussed their beliefs about end of life, and how they approach their diverse patients who are facing the end of life. There was a general agreement that it is easier to care for patients emotionally if a caregiver is aware of their own emotions and beliefs. This sentiment was slightly stronger among the not-for-profit nurses.

The Cycle of Observation and Belief

One of the important observations in this study was the cycle that took place between observation and beliefs. The nurses seemed to observe death through their spiritual lens, then appraise their beliefs in light of their observations. Subsequent observations were then observed
through their restructured spiritual lens, and the cycle continued. The cycle seemed to be an ongoing one in the life of a hospice nurse. This is not to suggest that their beliefs were inconsistent and ever-changing, but that their field of work gave them constant confirming or contradicting evidence for their beliefs. This is an important process, in light of the fact that the nurses felt that understanding one’s own beliefs is important to care giving. The important beliefs are formed by and on the caregiving they improve. Figure 1 depicts this cycle.

There were two different ways that the nurses formed their beliefs about the afterlife: formal doctrine, and observation. As previously stated, there is no dichotomy between doctrine and observation, rather a spectrum upon which every individual will tend to lean towards either forming their belief primarily on religious doctrine, or primarily on personal observation. This means that within the cycle above, some steps held more weight than others for different individuals. Either the observations heavily informed belief, or the spiritual lens was very dense. This is another aspect of one’s self that needs to be explored and understood to improve caregiving.

As previously discussed, the medical field is beginning to train professionals to be prepared for spiritual issues related to health and dying (Puchalski, 2008). As the participants in this study have shared, part of this preparedness is to be able to understand and articulate one’s own beliefs. Since this is the case, it would be beneficial, not only to prepare medical professionals to encounter the beliefs of their patients, but to evaluate and articulate their own. The findings suggest that a day-to-day awareness of the cycle of observation and beliefs and a conscious effort to recognize this process within oneself may be helpful to the emotional well-being of both nurses and the patients they care for. It may also be beneficial to both nurse and patient to recognize the dynamic between various religious doctrines. As the nurses shared: a Jew is not a Jew is not a Jew. The findings suggest that a sensitivity to the spectrum of beliefs that falls between strictly orthodox and strictly experiential is important in the day-to-day care giving for patients of diverse beliefs. Overall, a continuing improvement and growth in the spiritual education of health professionals is a good step in the right direction.

*The Importance of Care Philosophy*

The nurses’ education in medical, spiritual, and social matters played an important role in their work in non-hospice settings as well. Working in an ICU seemed to be a common stepping stone into hospice. The contrast between care philosophies seemed to represent opposite
extremes of the types of care. The ICU seemed to represent all that was fast-paced, barbaric, overbearing, disrespectful, and tyrannical. This is not to say that an ICU is unnecessary or inherently bad. The hospice care philosophy and the ICU care philosophy attempt to accomplish different ends, and therefore there is no good-bad comparison. However, from the vantage point of these nurses, their encounters with the ICU led them to favor the hospice philosophy and goal. Their descriptions of the ICU portrayed professionals who had to keep their patients alive at any cost to the patient, family, or nurse. Dying was considered a failure on the part of the healthcare professionals and, perhaps, the patient or their families. Patients that were rushed in after catastrophic accidents, heart attacks, and strokes were never asked, and in many cases they were in fact unable, to articulate their wishes. Often, there was no way to know if the patient had a DNR or a living will. Patients were sometimes revived at the expense of broken ribs, painful feeding tubes, brain damage, and other side effects. This was acknowledged as the nature of the beast. In the ICU, there was no time or means to do anything differently. Many of the nurses felt that they’d had enough of this approach and found its exact opposite in hospice, which values the humanity and comfort of the patient above all else. There was a peace in knowing that patients were ‘allowed’ to die, and that it was not a failure, but an inevitability. They felt a sense of freedom being able to spend quality time with patients and get to know them. This has implications for policy and education that surpass the scope of this paper. This study did not focus on nurses with experience working in an ICU, but these findings open up opportunities for future studies.

Diversity

Nurses stressed the prevalence of diversity within cultural and religious categories. Sociologist, H.W. Pfautz (1955) described the dynamic evolutions of cults, sects, denominations, and churches half a century ago. His theories remain viable today. This dynamic process of developing new groups as well as trends within groups towards and away from orthodoxy and traditional beliefs all lead to one reality: religion and spirituality are diverse and ever-changing landscapes. Orthodox Jews regard death differently from Reconstructionist Jews, and their burial practices reflect this. Diversity training, or cultural education was only mentioned in interviews twice, and briefly. One of these times was to share that the not-for-profit hospice employed a diversity coordinator, and that they were helpful to the hospice team. However, weighing the
number of socio-religiously sensitive stories shared against the two mentions of diversity training presented some concerns. This concern is something to be explored in a future study.

Walent (2008) asks a question that is rooted in the same line of inquiry as those in this study. Among his many questions, he asks, “How can a scientist within one spiritual/religious system grasp the meanings and beliefs of those whose religious and spiritual practices are rooted in different traditions and world views?” While Walnet is dealing specifically with researches and not healthcare providers, the essence of the question is the same. How can professionals encounter and handle religion or spirituality in a way “that recognizes and accounts for variations in individual and cultural journeys while remaining open and sensitive to the varieties of religious experience?”

The answer must begin with an understanding and ‘owning up to’ pre-understanding or prejudices. It is unrealistic for any individual to claim to have no beliefs. Even people who do not ascribe to a particular religion or philosophy have a worldview that is influenced by their experiences. Being clear and honest with oneself and colleagues will make the bridge between two different worldviews easier to build.

This process is confirmed by the experiences shared by the nurses in this study. All the participants agreed that understanding one’s own beliefs was important to being able to understand and care for another in the context of their beliefs.

**Implications**

The most important implication of this study is the affirmed importance of diversity training for medical professionals. Medical professionals have been educated in spiritual and cultural considerations in the past decade, and this trend must continue. This researcher’s experience of diversity training was a folder of information that is distributed with each employee’s orientation. The folder had a one-page summary of every common religion and culture, listing common practices, core beliefs, and things not to do with patients of this cultural or religious orientation. This approach seemed to suffice, however it may be beneficial to the field to develop more in-depth training. The most important practice will always be to ask patients what they want and expect at the end of life.

In terms of policy, this study did not specifically address the way that politics and policy effected the participants’ day-to-day lives, however, the topic did come up in a few interviews, especially regarding paperwork and insurance. The interviewee, Sam, said,
Years ago when nursing evolved it was about keeping the patient comfortable and it has all too easily become in to a world of ‘We have to make sure the I’s are dotted, T’s are crossed; make sure that this form, this form and this form is filled out because of this situation. Make sure all this extra documentation is put in place’ and then they forget what the true priority should be.

It is outside the scope of this study to give recommendations on this issue, however, it may benefit hospice workers and patients to reevaluate this aspect of the system.

Limitations and Future Studies

The limitations of this study were a lack of generalizability, which is inherent to qualitative research with small sample sizes. The interviews were usually between 60-90 minutes, this is considered to be a short interview. More findings may have been drawn out if interviews had been longer, however due to the fast-paced, round-the-clock nature of hospice care this was not possible.

Future research may profit to explore aspects of hospice such as diversity training, ways to improve record-keeping without impeding caregiving, and best practices to prepare families for grief. As hospice becomes more commonly used and less taboo, it will be beneficial to explore the experiences of caregivers to continue to improve the practices of hospice.

Conclusion

This study explored three main areas of inquiry as pertaining to hospice nurses: First, to understand how hospice nurses describe their own beliefs about end of life. Second, to describe the relationship between a nurse’s beliefs and the daily tasks of caregiving for patients and their families. Finally, to determine whether there is a difference in the attitudes of nurses between a for-profit and a not-for-profit hospice. The twelve participants from a for-profit and a not-for-profit hospice shared their beliefs and views within these three inquiries via in-depth interviews. The researcher found that the nurses were willing to share their deeply-held beliefs about the importance of comfort and minimizing the burden on the patient. The participants all formed their beliefs based on formal doctrine, observations they’ve had in their work, or usually, a mixture of both. The nurses valued and respected a diversity of beliefs among their patients, and even within the different religious and cultural groups. Intra-religious diversity needed to be approached with sensitivity and self-awareness. All the participants felt that in order to care for patients with diverse beliefs, they needed to understand their own beliefs, however, this idea was spoken more strongly among the not-for-profit nurses. The main implication of these findings is
that there needs to be a continuing improvement and assessment of the diversity training and education, especially in terms of religion and spirituality.
Appendix

Table 1: Participant Descriptions

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<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Environment</th>
<th>Interview #</th>
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<td>For-Profit</td>
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Figure 1: The Cycle of Observation and Belief

A death/event is observed through a spiritual "lens".

Spiritual beliefs are appraised in light of observation.

The spiritual "lens" is refined to include the new observation.
Figure 2: Participant Consent Form

Dear participant:

My name is Sarah Atala and I am a graduate student in Gerontology at Miami University. My faculty advisor is Dr. Kate de Medeiros.

You are invited to participate in a research study about how hospice nurses view their work and if their beliefs on spirituality, religion, or philosophies are important to the work. To participate you must have worked in Hospice care for one uninterrupted year before the interview. You will be asked to complete an approximately 60 to 90 minute interview that will be audio-recorded. The interviews will be confidential and stored in a secure location for the duration of the project. The only ones who will have access to the information will be myself and my faculty advisor. The data will be destroyed after analysis. Through confidentiality no participant will be able to be linked to any response he or she provides to the researcher.

The benefit of the study is to help us understand how hospice nurses view their own beliefs and the importance it hold in their jobs. At the end of the study, I will make general results available to you. The generalized results may be presented at professional conferences or published in articles describing the results of the research. I may use direct quotes from interviews in my presentations, but there will be no identifying information associated with them.

Your participation is voluntary and you may withdraw from the session at any time or decline to answer any questions that make you uncomfortable. If you chose to leave the session before its end you will not be penalized. You will not be asked to do anything that exposes you to risks. Upon transcription I will remove all names and other identifying information from the transcript. Your responses will not be linked to you. Audio files and paper copies will be stored on a USB drive in a locked drawer accessible only to me. All files will be destroyed after completion of the project.

If you have further questions or concerns about participating in the study please contact

Sarah Atala at ###-###-#### name@miamioh.edu

Dr. Kate de Medeiros at ###-###-#### name@miamioh.edu.

If you have questions about your rights as a research participant, please call

Office of Advancement of Research and Scholarship at 513-529-3600 humansubjects@miamioh.edu.

Thank you for your participation. We are very grateful for your help and hope that this will be an interesting session for you. You may keep this portion of the page.

Cut at the line, keep the top section and return the bottom section.

I agree to participate in the study of how hospice nurses view their own beliefs and the importance it holds in their jobs. I understand my participation is voluntary and that my name will not be associated with my responses. By signing below, I acknowledge that I am 18 years or older.

Print name: ___________________________________________

Participant’s signature _______________________________ Date: __________

☐ I give permission to be audio recorded. (Check if yes.)
References:


