“IT’S OUR HONOR TO WALK THEM THROUGH THIS JOURNEY”: HOSPICE WORKERS AND HOW THEY CONCEPTUALIZE THEIR WORK AND THE DYING PROCESS

A Thesis Presented to
The Faculty of the Department of Sociology
Colorado College

In Partial Fulfillment of the Requirements for the Degree
Bachelor of Arts in Sociology

Eliza Jacobson
December 2016

On my honor, I have neither given nor received unauthorized aid on this thesis

Eliza Jacobson

ACKNOWLEDGEMENTS

Thank you to Vanessa Muñoz for guiding me through this process, and encouraging me even when I was convinced that the final product would never come together.

Thank you to my parents for listening to me everyday on the phone as I overanalyzed every interview I conducted and every word I wrote down on the page.

Dedicated to my grandma, Fan Scheier, who passed away a month after this thesis was submitted. She was the most loving grandmother a girl could ask for, and was my biggest fan from day one.

ABSTRACT

This research aims to understand how hospice workers conceptualize their jobs and the dying process in a death phobic society, and a medical field where extending life is almost always the primary goal. I used Everett Hughes' theory of dirty work to examine how hospice employees construct meaning of their occupations. I conducted 10 in-depth face-to-face interviews with certified nursing assistants, nurses, physician assistants, social workers, and administrators. I found that that these hospice workers contextualize their work as being more rewarding than other areas of treatment through a patient driven practice that empowers the dying to have agency over their end-of-life experiences. They also frame their work as either a calling or a natural ability, seeing their work as an honor and a source of insight into both life and death.

TABLE OF CONTENTS

Appendices

Many Americans attempt to avoid death at all costs, whether in casual conversation, making end-of-life plans, or the life process itself. Innovations in medical technologies have made this easier, holding the promise that anything can be cured and life can almost always be prolonged. According to a 2013 study nearly 31 percent of Americans reported that medical professionals should do everything possible to save a patient, even in dire circumstances. While this number translates to only about one third of the population, it has doubled since 1990 (Pew forum 2013). Yet death is a certainty no matter how distant it may feel. It is also a reality hospice employees are confronted with everyday when they go to work.

Most People associate hospice with loss of hope, morbidity, and failure, and attach the negative taboos of death and dying onto it as well. Yet hospices express a sentiment in contrast to that of general society: “Hospice seeks to empower the patient…It focuses on LIVING rather than dying” (Angela Hospice 2017). How do these workers make meaning of their work and of the dying process in a death phobic society and a medical field where extending life is almost always the primary goal? In this thesis I argue that hospice workers contextualize their work as being more rewarding than other areas of treatment through a patient driven practice that empowers the dying to have agency over their own end-of-life experiences. They frame their work as either a calling or a natural ability, seeing their work as an honor and a source of insight into both life and death.

LITERATURE REVIEW

In order to understand how hospice workers make meaning of their work it is important to contextualize their experiences shaped by a society that values the medicalization of death and therefore considers hospice work dirty work. Embedding them in the greater theoretical framework of identity construction and emotional labor is also crucial in interpreting these findings.

Medicalization of Death and Medical Authority

In modern American society the medical establishment holds great authority. When people are sick they go to the doctor, wanting expert opinions and cures for their ailments that only those with the proper degree can prescribe. Naturally occurring processes are increasingly becoming medicalized, with new medical treatments being created to "cure" these problems (Conrad 1992). With medicalization also comes the rise in medical authority, where medical professionals hold the power to dictate how to behave in all situations newly considered medical (Conrad and Schneider 1980). The dying process has recently become medicalized; what historically took place in the home but has shifted to the sterility of a hospital room. Zweig and Oliver (2009:177) write, "dying loved ones became dying patients, and those dying patients had goals in conflict with the saving nature of medicine, causing them to be seen as failures." When death became medical, society forgot that it was natural. Moving the dying process into the hospital established death as the ultimate defeat (Zweig & Oliver 2009). Death in the Intensive Care Unit (ICU) may be the epitome of the medicalization of death and the antithesis of the natural dying process, where patients on the verge of death are subject to extreme life-prolonging measures (Seymour 2000). Jane Seymour (1999:694) writes about the dying in the ICU:

> when it occurs, death in intensive care is almost always categorized by extreme vulnerability and bodily dependence of the dying person, and by an apparent lack, or impairment of, their awareness of 'self… most critically, the exercise of

> choice, control and self-determination by the dying person, so central to the various ideologies of good and natural death, impossible

Most significantly, patients' lose their agency and they are unable to control their end-of-life experiences. While the ICU is an extreme example of this phenomenon it illustrates the normalizing of the medicalization of death

Hospice as Dirty Work

Everett Hughes (1951) introduced the idea of "dirty" work to mean occupations that are valued by greater society as undesirable and disgusting. There are three taints that categorize work as dirty: physical taint, social taint, or moral taint. Two of the three, physical and social taint, can be attributed to hospice work. An occupation with physical taint is one where workers tangibly interact with subjects that are considered dirty and disgusting, or a job that employees perform under unsatisfactory conditions. Hospice care has a physical taint because it deals directly with death, illness, and diseased bodies (Ashforth and Kriener 1999). These dirty subjects, however, are not innately dirty. Mary Douglas (1966: 35) writes, "dirt…is never a unique, isolated event. Where there is dirt there is a system." It is the social meaning given to death, illness, and diseased bodies that invoke such a strong distaste for them and the work associated (Douglas, 1966; Lawton, 1998). Occupations that deal with the corporeal body are stigmatized and therefore fall low on the social hierarchy (Twigg 2000). Social taint refers to a job where workers must confront groups of marginalized people on a daily basis. The clients of hospice care fall into this category, as they are the elderly, the diseased, and the dying (Ashforth and Kreiner, 415; Twigg, 2000). Ashforth and Kreiner write (1999: 416), "Although people may applaud certain dirty work as noble, they generally remain psychologically and behaviorally distanced from that work and those who do it, glad that it is someone else." Hospice work, while it is dirty, is seen as good work and may be praised by people who do not perform it. Yet many still distance themselves from it because they do not want to associate with the social taboos that the work represents.

The stigmatization does not only fall onto the occupation, however, but can be transferred to the workers themselves (Ashforth and Kreiner 1999). Although society's perceptions of this work are not about the actual characteristics of the job and more about the innate responses many people have to these characteristics, this still can pose a threat to the construction of a positive self-identity. As Gini writes (1998: 708), "It is in work we become persons. Work is that which forms us, gives us a focus, gives us a vehicle for personal expression and offers us a means for personal definition." Human beings are defined by what they do, and if they perform dirty work society will then define them in terms of the socially constructed meanings associated with their occupation. Even though these workers are stigmatized by society, however, there are two major ways they construct positive self-identity in the face of misunderstanding.

Reframing

One of the many ways dirty workers do this is through the process of reframing (Ashforth and Kreiner 1999). Reframing refers to the process of turning negative characterizations of dirty work on their heads and transforming them into positive components of the job (Ashforth and Kreiner 1999). There are many ways in which hospice workers reframe the taboo subjects of death and dying. Many describe their work and having the opportunity to be a part of the dying process as a gift and an honor. Instead of focusing on the physical grotesqueness and morbidity of death, these workers choose to describe death as something sacred and profound. They portray their occupations as a calling, something that they were meant to be doing, and feel that they are presented with chance to make a significant impact in someone's life by turning the taboo subject of death into a peaceful and meaningful experience (White & Gilstrap, 2016; Mcnamara 1995, Waddell, and Colvin, 1995; Cain, 2012). Huppatz (2010: 74) writes about nurses and how they want their jobs to be respected so they, "attempt to make occupations respectable and this in turn, provides the workers themselves with respectability." This reframing also allows hospice workers to make positive meaning and justify the values of the work they do (McNamara et al 1995).

Workers may also reframe the social taboos associated with their jobs through comedy and humor. Cain (2012) studied hospice workers' front and backstage presentations of self. She closely examined their use of dark humor as a coping mechanism performed in the backstage arena. By shifting the way they talk about death and dying from sad and depressing to light and playful they can make sense of and deal with the heavy subjects they are presented with everyday. Joking about this work also reminds workers that death and the dying process are out of their hands, and that talk and laughter is a way to find relief and acceptance of the subject matter of their work, which they do not have the power to control (Tracey, Myers, and Scott, 2006). This humor is a way for hospice workers to express that they understand that death is a natural part of life, and can sometimes even be a little funny. If there was no outlet for laughter all the workers would do is cry.

Insiders versus outsiders

Another strategy used by dirty workers to create positive self-identity in the face of stigmatization is by defining their groups from the groups outside of them. This mentality allows workers in the "in-group" to create strong bonds with those around them (Ashforth and Kreiner 1999). Working with death and dying allows hospice workers to see and learn things that people in different fields will never get to experience. Cain (2012: 684) writes, "Several staff said that outsiders often do not understand that hospice is not sad because they become accustomed to death and accept it as inevitable." Hospice workers' experiences in becoming a part of the dying process, one of the most significant moments in life that most outsiders often avoid, shape their perceptions of life and death. In many cases it is difficult for these workers to share the insights and viewpoints they foster in their work with those outside of the field, and outsiders tend to ignore or avoid these discussions altogether. Moreover, many do not even discuss these issues with their friends and family members due to their different backgrounds of understanding.

Hospice workers also feel that they are privileged to do this work, a sentiment people outside of the field typically do not understand (McNamara et al. 1995). Many also explain that they were meant to work in hospice, citing their entrance into the field as a calling or inherent ability (White & Gilstrap 2016). Twigg (2000: 165) writes, "though workers regard the work as skilled and demanding, they also see it as something that is natural, or at least natural to people like themselves." Hospice work is a job one can either do or cannot do, a job that one must posses a natural inclination for. Hospice workers do not disparage those who are not fit for it, however, this outlook does create a barrier between the two groups.

McNamara et al (1995) also found that the hospice nurses they interviewed had a tendency to compare themselves and their work to traditional medical institutions such as the hospital. They write (1995:237), "…the nursing staff find justification in their expertise in telling stories amongst themselves about hospitals' failures to cope with the terminally ill patients…hospice staff express similar forms of criticism which they use to justify their own practices." By criticizing the methods of those outside of their group they validate their own beliefs and practices and define their group and the work they do with higher value (McNamara et al 1995).

Hospice Work as Emotional Labor

Emotional labor is work that involves or is founded on responding to and handling clients' emotions. James (1988:19) writes, "emotional labor is hard work and can be sorrowful and difficult. It demands that the laborer gives personal attention which means they must give something of themselves, not just a formulaic response." While all nursing can be placed under the umbrella of emotional labor much of hospice work is defined by the emotion work involved, especially working with the families of dying loved ones (Cooper and Mitchell 1990). Hospice care goes past the practical medical responsibilities of a typical healthcare career because it deals with the real and raw feelings of patients and their families at the end of life, an intensely private and meaningful time (Charmaz, 1980). James (1988) also found that when interviewing hospice workers many reported that their job did not feel complete if they had not performed some sort of emotional work with their clients. The day-to-day medical duties of the nurses are not what make them passionate in their careers; it is the deep and emotionally driven interactions that make them feel fulfilled in their work.

For employees, controlling and managing their own emotions on the job is an important component of performing emotional labor. Traditionally, the workplace is supposed to be devoid of emotion because it is the antithesis of logic and rationality

(James 1988). There are prescribed “feeling rules,” for different places, normal and solidified ways to act in certain places (Hochschild, 1979). But when an occupation requires one to be, and is based upon, dealing with the emotions of others there are professional limitations workers are expected to recognize. Hochschild (1979:568) writes, “any gesture-a cool greeting, an appreciative laugh, the apology for an outburst-is measured against a prior sense of what is reasonably owed another, given the sort of bond involved.” Hospice employees are expected to show compassion and care for the family, yet they still must maintain professional boundaries. Nurses and social workers cannot appear to be made of stone, because then their emotions are not viewed as genuine and therefore they are not performing their tasks well. Yet on the other hand they cannot break down and cry in front of a family or act in any way that would make the patient feel burdened. Hochschild (1979:561) describes ‘emotion work’ as, “the act of evoking or shaping, as well as suppressing, feeling in oneself.” Hospice workers can express and show emotion, but they must manage their performance so as not to cross the invisible line.

Identity Construction in the Social World

Human beings living in the social world do not exist in a vacuum. Cooley (1983: 266) argues that the way we view ourselves is based on the people around us. He writes, “…in imagination we perceive in another’s mind some thought of our appearance, manners, aims, deeds, character, friends, and so on, and are variously affected by it.” This can also apply to self perceptions based on occupations. What we do is who we are. The first information exchanged with a stranger typically includes what one does for a living. At a dinner party or sitting on a plane people tend to ask of their new acquaintance’s occupation (Thompson: 404). Self-theorists posit that people create their self-evaluations based on their interchanges with the people and objects around them and these "confrontations generate the positive or negative self-evaluative information that people rely on to reach conclusions about themselves as social objects" (Schwalbe 1998: 25). Thus hospice workers, like workers in every field, too will internalize their ideas about how others view them and use this information to create meanings about themselves. What makes hospice work different from other fields are the taboos greater society has ascribed to it, which then leads outsiders to misunderstand their work. It is also a field where the primary goal is to comfort patients and their families and to make them feel safe. This makes positive feedback and ability to make a meaningful impact in another's life significant in construction of occupational identity, because this work is based upon the feelings of others.

Quinn-Lee, Olson-Mcbride, and Unterberger (2014) discovered that the hospice nurses they interviewed found fulfillment in the praise they get from their patients and their patients' families. Stacey (2005: 850) writes, "pride and honor come from being able to affect positively the emotional state of clients." When nurses see that their hard work is making a significant difference in their patients' lives they internalize this information and therefore see themselves in a positive light. Huppatz (2010) extends this idea of self-perception to discuss the idea of respectability based on occupation. In her study of nurses, a traditional career for women, she found that respectability only exists within the realm of social relationships. There must always be an audience present in order to make meaning.

Views on Life and Death

Hospice workers are one of the few groups of people who gain insight into the world of death and dying that most people avoid. There is a common misconception that working with those at the end-of-life is morbid, and an assumption that hospice workers and others employees in the death industry are forced to confront their own mortality on a daily basis. Working in hospice, however, leads to decreased levels in death anxiety compared to hospital nurses (Quinn-Lee et al. 2014; Cooper and Mitchell 1990). This is because hospital nurses work in a field where they are instilled with the ideas that death is the ultimate failure. McNamara et al (1995: 240) write, “both societal attitudes and those of mainstream medicine therefore have contributed to the association of death with failure. Failure is further implicitly associated with something which is bad.” When death is taken out of this context, as it is in hospice care, then people who are surrounded by it do not attach the same meanings to the process. Additionally, the longer time spent working in hospice the more comfortable workers are about their own eventual death. They must become somewhat accustomed to the dying process because it is something that they deal with and confront every day. They see that death can be a peaceful and calm process when there are people available to provide good conditions, compassion, and support (Quinn-Lee et al. 2014).

Working in an occupation that confronts the dying process not only impacts hospice workers views on death. This so called morbid work also gives new meaning to living and life. McNamara et al (1995: 240) write, “their [hospice workers] value system is based, not only on facilitating a ‘good’ death, but also on living a ‘good’ life.” Being confronted with illness and death everyday shapes perceptions of life for those in the hospice field. Cain (2012: 685) quotes a hospice chaplain, “this is where the juice of life is." Spending time with those facing their final moments is part of an average day in hospice. Workers, especially nurses and certified nursing assistants (CNAS), visit with many dying patients daily while on the clock. The stories they hear and the lessons they learn from these people have the ability to change the way they view and live their own lives. Mcnamara et al (1995:240) write, "sometimes the dying person's expressions of lost opportunities, or mistakes made, influences the nurses' re-evaluation s of their own lives..." Hospice care is about living, whether it pertains to the patient making the most of their last days or the lives of the nurses who work at their bedsides.

Previous literature explores hospice workers' conceptions of their positions and how they construct positive self-identity, however, examination into the patient-driven nature of hospice and how that impacts workers is ignored. In many ways hospice is about empowering the dying and giving them the agency to take control over their death processes when they did not have the opportunity to do so before. Yet there has been no connection made between this and the self-identity construction of hospice workers. In this thesis I will focus on this connection and how it relates to the way hospice workers frame their work in terms of a calling or natural ability, and how they see their work as an honor and source of insight into life and death.

METHODS

Sample

To explore this issue more deeply I conducted interviews with ten hospice employees, nine of which worked for Synergy Hospice Care[1], the largest and oldest hospice facility in the metropolitan area. They are the only non-profit and community-

---

[1] All names have been changed to protect the identity of my interviewees and their place of work

based organization in the county and provide home care and travel to nursing homes and assisted living facilities, as well as having an inpatient unit at a local hospital. I gained access to this community through a friend who had volunteered with the organization a year prior to the start of my research. She provided me with the emails of two volunteer coordinators. They then referred me to the Vice President of clinical programs who sent an email to the entire staff, providing them with my contact information so they could reach out to me if they wished to take part in the study. I told participants my study was about the lived experiences of hospice workers and how they view their work. The only criterion for participation in my study was that participants were medically trained. This changed, however, and I allowed all those who contacted me to participate due to the time limitations and self-selection process. Additionally, a colleague in the community referred me to the one participant not associated with Synergy Hospice Care.

The level of education my participants held ranged from some college to masters degrees. My sample included four registered nurses (RN), one nurse practitioner, three certified nursing assistants (CNA), one social worker, and one member of the administration who had worked as a hospice RN in years prior. Nine participants were female and one was male. Their ages ranged from 27 to 59 years old, and their time spent working in hospice ranged from two to ten years. Three reported that they did not affiliate with any religions, four stated that they were Christians, one was a Christian Protestant, one identified as a Methodist, while one was a past practicing Catholic with Christian beliefs.

Instrument and Procedure

Before beginning the interview process I constructed an interview guide, based on Kathy Charmaz's (2006) guidelines on conducting grounded theory research and gathering rich data. The original guide consisted of 43 questions, which were broken down into three main sections including entering the medical field/hospice work, experiences at work, and views on death and dying. One question in my conclusion section asked my interviewees to suggest possible questions for future interviews. Based on these suggestions I added questions to my guide as I continued my research.

As for my interview process, I conducted in-depth interviews lasting between 50 and 120 minutes in various locations most convenient for my participants, including the local Hospital, the Synergy Hospice Care main office, community coffee shops, and one participant's home. Before starting the interview I informed every participant of IRB guidelines and they all signed an IRB approved consent form that described how taking part in the research was voluntary and that all responses would remain confidential. I then asked if I could record each interview, and all interviewees agreed. I informed them that I would be the only person to listen to these recordings and that they would be erased after transcription. After this step I then proceeded to interview, following my interview guide but also asking organically formed probes and follow up questions as we went along. At the end of the interviews I asked participants to fill out a demographic questionnaire asking about things such as their religious affiliations, highest levels of education, and years involved in hospice. Nine out of ten participants filled out this form, and one was in a rush to leave the interview and did not get the chance to. I then gave my participants cookies as a sign of my gratitude for taking part in my research. All interviews were recorded on my phone and on a backup recorder and then were transcribed verbatim for future coding. When writing my paper, however, I removed “ums” and repeated words from the quotes I used.

Data Analysis

To analyze my data I read through every interview. When reading I looked for similar themes and highlighted quotes, noting in the margins the theme each quote fell into. While reading each interview I copied and pasted these quotes into different documents according to theme. The themes included outsiders vs. insiders, reframing, views on death and dying, self-identity based on others’ perceptions, emotion management, and outliers. After categorizing in this way I went through each theme page and created smaller and more specific themes. I continued this process multiple times, reorganizing and solidifying my findings.

Methodological Limitations

I was limited by my role as a researcher with no personal experience with death and having known no one close to me who had been on hospice care. There were points in my interviews in which it would have been helpful to emotionally connect with my interviewees in order to gain better insight into their work as well as how their own lives and histories impacted their understanding of their current positions. In addition, many of my interviewees were overtly grateful and thanked me for taking the time to do this study, even though they were making a sacrifice in their day for *my* research project. This led me to infer that they do not get the chance to express themselves in this way very often. Because of this they may have been hesitant to relay information about their work that could attribute negatively to hospice. Finally, due to the nature of my recruitment method my sample was self-selected, meaning that all of my participants presented as white and 90 percent of them identified as female. This allowed for little exploration into the possible racial and gendered dynamics of this type of work.

FINDINGS

The hospice workers I got the chance to interview were filled with a multitude of insights, ideas, and stories that illuminated how they make meaning of their work and the dying process in a society that is avoidant and misunderstanding of their field. I argue that hospice workers contextualize their work as being more rewarding than other areas of treatment through a patient driven practice that empowers the dying to have agency over their end-of-life experiences. They frame their work as either a calling or a natural ability, seeing their work as an honor and a source of insight into both life and death.

"You get to be the captain of the ship"

Hospice is patient driven, and professional staff step back to support and let their clients make the decisions they want for themselves at the end-of-life. In other medical fields the goals are curative, and patients are pushed to recover, therefore, they must follow medical orders and do what they are told if they want to survive. In hospice, however, dying is accepted and the goal is not to cure but to facilitate a comfortable death. Rachel, a hospice RN of about ten years, spoke about the process she underwent when she entered the field, accepting that the hospice philosophy urged her to put her own views aside in order to help her patients fulfill their last wishes. She said, "I tell people, you know, you get to be the captain of the ship, you know, you've been told all along that you have to take this medication and we're not gonna tell you you have to. I might tell you why you might want to, but ultimately the choice is yours because this is your life, and you get to choose now." The main goal of other nursing jobs Rachel had prior to hospice was to help patients get cured and recover, allowing for heavy reliance on medical expertise. She said, “I think I would really push someone to do what I wanted them to and I had my reasons you know like, ‘you should take this medication because this this and this’ or you know, ‘you really have to you know follow up on such and such.’” But once the emphasis on curative care was removed and focus shifted instead to quality of a patient’s remaining days she learned to let go and step out of the driver’s seat, transferring her title of expert onto the patient.

Mary, who became a hospice RN as a second career and has been working in the field for seven years, had a similar change in mindset when she first started doing this work. Her realization came from her own experience with her grandmother’s death, which had not been “good” as she would have defined it, yet led her to become a hospice nurse and changed the course of her life. She said, “when I first came into hospice I thought my role as a nurse was to make sure everybody has a ‘good’ death, I learned that is not my role, and how arrogant of me to think that...” Like Rachel, she had ideas about what would be best for her patients and believed it was her mission to make sure their deaths were more in line with this vision of a good death than the chaotic death she had experienced. Yet working in hospice made her realize that her duty was not to force her conceptions of what was best for her patients onto them. In this way she expressed the sentiment that during this intimate time of death there is no one with more authority than the dying person, and that it is not the role of hospice workers to interfere with that in any way. This gives agency to the elderly and the sick, populations that have been historically marginalized in society.

Emily, a former hospice RN and now a member of Synergy Hospice Care's administration, also realized that her vision of a good death was not a universal one. She envisioned nice music playing and the family standing around the bedside of the dying patient, all grudges and struggles in life resolved before passing on, "so the first six months that's what I would try to create for people whether they wanted it or not," she said, "and then I had a couple patients that kind of woke me up and made me realize that no, 'that's not what I want,' and that was when I realized that I needed to help them create the death that they wanted, not the death that I wanted." Emily, like Mary, had admirable intentions but was forced to realize that hospice is about giving a voice to the patients that were not listened to before. Being able to provide this support and make an impact on these patients' lives also proved to be highly valued by my interviewees.

Patient driven care is what all members of my sample described as a main tenant of hospice. When asked about the most rewarding aspect of their jobs, interviewees described being fulfilled by having the ability to help their patients facilitate their end-of-life wishes and to fully support their families. Cindy decided to become a CNA when her father fell ill so she could take the role as his primary caregiver. After he passed away she followed in her daughter's footsteps and applied to work at Synergy Hospice Care. She explained why she finds her work gratifying:

> I can't tell you sometimes how relieved people are when they find out, 'I don't have to go to the doctor,' you know, 'I don't have to leave my house if I don't want, if I don't wanna eat its ok.' It is rewarding because they've lost so much and they've lost a lot of power in their lives where they have no control over so many things that it's nice that we're able to give them some control over their own life, and what they want and what they don't want

Being the one to help these people regain control of their lives and find relief made Cindy feel that she was doing good work. She expressed that many of her patients felt social pressure to continue keeping up with visits to the doctor and frequent medical tests, but when coming to hospice they can let go of these norms and expectations and simply surrender to this natural life process. She found great value in having that ability to be there for them during this time and giving them a say in how they want to spend their last days.

Emily echoed these ideas when she described the educational component of working in hospice and palliative medicine:

> that was one of the most rewarding parts was just going to these rooms and having those conversations with patients and families about ‘what’s really important to you right now,’ you know, and, ‘what do you wanna do with the rest of your life?’ and so that was truly an amazing experience

Emily used her medical knowledge and training not to tell patients and families what to do and how to live their lives but to empower them with education so they could make their own choices. Giving this gift to people made her feel valued for her work while also giving agency to her dying patients.

Lucy, a CNA for two years, viewed her job in a similar way. When asked what the most rewarding part of working in hospice was for her she responded, “at the end of the day, I can say that I made a difference in someone’s life; I helped somebody, that’s it. It makes me feel good. I mean, it means that I’ve done something to make a difference and I didn’t have to go put out a fire or anything like that. I just did my job so.” Lucy felt accomplished by doing this work and making an impact in her patients’ lives. On the other hand, by describing her duties in this way, she downplayed the skill it takes to work as a hospice CNA. Her statement also somewhat devalued the effort and hard work she puts into her job by summing up her ability to do this work as just a natural affinity. Furthermore, making the comparison to putting out a fire as a feat that requires bravery and should be met with glory made her job seem less worthy. Yet she, like the majority of my interviewees, was humble and also grateful for her ability to succeed in her career. She did not believe that she should be singled out and celebrated because she felt that she is simply living out the life she was meant to lead. This is another way she puts her patients first; she deflects this attention and expressed that this work is not about her and her selfless abilities.

Only one member of my sample, Sam, expressed that hospice workers deserved outsiders' praise and admiration for their work. He spoke about a situation in his past job where he became too close to a patient, acting more like a best friend than a caregiver by taking him on trips and spending time with him after work hours. He lost control of his ego, indulging in the compliments he received from outsiders for going above and beyond. Although he explained that he felt regret after hurting this patient when he moved away and had to limit contact with him, he stated, "you do get attention for working where you work and doing what you do, as in some ways rightfully you should because not everybody can do it." The majority of interviewees reported that they were not commonly met with this positive recognition, oftentimes receiving exclamations such as "How do you do that?" and "That must be so sad" in response to sharing their careers with others. Cindy and Lucy did state that they were met with gratitude for being hospice workers, yet they were both humble in the face of this attention. Sam, on the other hand, believed that this praise and glory is somewhat warranted because he and his fellow hospice employees are performing tasks most outsiders would never even think of doing and furthermore do not have the natural abilities to do. To him the rewarding aspect of this career is receiving admiration not only from his clients but *also* from those not associated with hospice, giving him a sense of pride that extends beyond the confines of his professional identity. His thoughts on this matter are almost in stark opposition to Lucy's, who asserted that at the end of the day she feels valued because she knows she helped a patient and did not have to put out a fire to do so. While Lucy downplayed her ability to do hospice work as only natural and therefore devoid of effort and skill, Sam welcomed the idea that people should acknowledge how difficult their work is and applaud them *because* of their natural abilities that allow them to do this work. One possible explanation for this shift in sentiment can be explained by the fact that Sam was the only male interviewee in my sample. Females traditionally staff careers in carework, so when men take on tasks such as working in hospice they may be viewed as admirable and heroic, performing duties that are typically performed by women. Members of the public will generally glorify a man doing things such as nurturing a baby or comforting a crying little girl, whereas they commonly ignore a woman doing these same things because they believe it is just her natural inclination to care.

Many of my interviewees also described working in hospice as the most rewarding job they had ever had. In comparison to other nursing jobs and positions outside of the field, hospice is where they felt they could make the most impact and therefore feel the most valued. Rachel discussed how fun and fulfilling working in hospice is for her, illustrating this point with an example about watching a man get his pain under control and regaining the ability to get out of the house and watch his son play soccer. She said, "to have that experience is just incredible; to be able to know that you've helped them and made a difference so quickly. So this is the actually, this is the most fulfilling nursing area that I've ever worked where you can make that kind of difference in someone's lives and the family too." Rachel again emphasized that her ability to make a positive difference in the lives of her patients and their families is what makes her feel accomplished, but adds that the nature of hospice work makes that positive difference more rewarding. To eliminate the goal of curing someone and instead focusing on guiding patients in reaching their end-of-life wishes makes it easier to have that impact in someone's life. This goes back to the relinquishing of total medical authority and giving the patients a voice, providing not only gratification for the patient but also the professional. Molly, an RN who has been working in hospice for two years, agreed when she described the most rewarding aspect of the job:

> I'm actually doing something…anybody can push pain medicine you know, anybody can do this job…but at *this* job I don't feel that way you know. Like most people when I go to homecare, you know, they're very grateful that you're there. There's few people who complain. But yeah, I think that's what it is, that I actually enjoy my job and that I feel appreciated for what I do

Before hospice Molly had worked in a long-term acute care hospital, aiding people with chronic conditions. She explained, however, that her current job is where she feels the most valued, again because of her ability to make a difference in her patients' lives and their open appreciation of her willingness to be there for them. She highlighted this ability to do hospice work when she made a comparison between her previous job and her current position, stating that anyone can sling medicine and insinuating that not everyone can do hospice. This is significant because Molly described her natural affinity for hospice somewhat similarly to Sam, acknowledging that her work is challenging and intensive and that it should not be devalued in any way.

Hospice social worker Lauren also felt that her time in hospice is when she can provide the most valuable service and in turn felt that it has been her most fruitful career:

> I feel like we're actually providing a good service that's a valuable service to people at the end-of-life rather than just, I'm not sure, other kinds of social work where a child, there's suspected abuse and you have to take the kid out of the home and it's a he said she said. It's, it doesn't seem to be a valuable type of service where hospice work it seems like we're actually providing that comfort and peace for people. So I feel it's a little more valuable

Lauren comes from a different background than Rachel and Molly because she is not a medically trained professional, so she spoke about her previous careers in social work. Hospice is the most significant work she has done because she feels that she can make a major impact on her patients' lives and can actually see the results and outcomes of her input. Lauren explained that the effort she puts into her job will pay off, whereas in other jobs she had it was much more difficult to reach goals because of the complexity of the clients she dealt with and the situations they were faced with. She inferred that aiding the patients in carrying out their end-of-life aspirations made her feel accomplished because, while it is difficult and emotionally taxing, the path to achievement is more straightforward than in her past work. Yet hospice is not for everyone, and every member of my sample expressed that it took a certain ability to claim it as a career. Even though hospice was the most rewarding job many of my interviewees had had, they also described that they were called upon to do it or that they were born with a natural aptitude fit for it.

"*I don't even think you can learn it, it's either in you or it's not"*

Many of my interviewees described their entrance into the world of hospice as something that they were called on to do, or that God had pushed them in the direction of this work. Mary stated, "What led me to where I am today was I think a, it's just where my life's journey was meant to go, I just didn't know it at the time." She continued, "I KNOW I need to be a hospice nurse." Except for one member of my sample, none of my interviewees stumbled upon hospice work or took the job primarily because of an available position or hefty salary. For three members of my sample, hospice was a second career after working in fields including teaching, administration, and bookkeeping. Cindy, a former administrator, described the intricate signs that proved to her that God was behind this shift in life, such as the closing of her office and a CNA school opening up right behind her house so close, "I could have jumped my fence and been in their backyard." She said, "I'm hard headed so it took God probably about that long to finally get through to me that this is where he…that was the path he wanted me to take… and it all sorta came together," and later she continued, "I just love it, I love it, I, I, sometimes you just know where you belong and I belong here." Though the power that pushed Cindy into hospice was in God's hands, this career turned out to be something that fit like a puzzle piece into her life and she expressed the passion and fulfillment that it brought her.

Like Cindy, other workers I interviewed believed that God was behind their journey to work in hospice, and even through difficult times he continued to help them reach this goal. Molly spoke about her process choosing a job after graduating high school, thinking through the subjects she really liked. She decided to enter nursing school, but found that it was more challenging than she had originally thought and almost did not finish. She stated, "I went through nursing school and it was a lot harder, and so I ran into a roadblock and I tried to quit. But I'm a Christian so God was like, 'no this is what I want you to do,' and so that's how I continued being a nurse. So it's my calling." Even when her path was filled with twists and turns becoming something she did not expect she felt that a greater power would guide her to this place, knowing in her heart that nursing was her calling and eventually realizing that hospice is where she belongs.

Not all interviewees described hospice in terms of being a calling or part of God's plan. Yet these other members of my sample explained that they possessed something innate that allowed them to be successful in hospice work. Many participants also highlighted that hospice work is either something you can do or you can't do, and it is not a job that you can teach to someone not meant for it. Lucy stated, "you're either fit for it or you're not, and you find that out real quick," and she later continued, "yeah you can either do it or you can't, like, I don't even think you can learn it, it's either in you or it's not." Lucy drew a line between people with the ability to work in hospice and those without it, further establishing that it is a field where one does not stay if they do not belong. When asked what advice she would give to someone wanting to enter the world of hospice, Anne responded:

> There's certain things in life and in nursing and anything that you can teach, you know. I can teach you how to give a blood pressure, take blood pressure, give meds, call the doctor and all that. You can teach those things, but there's something that you have to have that is just innate in you to be able to know…you need to be a little bit of a chameleon of sorts, but genuine, a genuine chameleon…so when you walk into a patient's house…you have to be able to walk into that home or that facility or whatever the situation is, and be exactly what they need you to be right then. So advice, I don't know, because you cant, that's the something you can't teach, and that's something I think what helps you be a good hospice nurse

Anne explained what she believes to be the characteristic successful in hospice that cannot be taught, and that is the ability to be exactly what the patient and the family need at all times. Every client prefers something different, so workers must find it in themselves to offer all they can in each changing situation. This work is about caring for others and making patients and their families feel comfortable, safe, and content in their last days of life. A hospice worker must have the natural instinct to do all they can to emotionally support their clients compassionately and genuinely and to acknowledge that they may have to do this in varying ways. This is not something that one can pretend; it must come from the heart.

Jen, an RN who had previously been a teacher and then a nurse in the ICU, explained that it was not only her work in critical care that prepared her for hospice, but also the characteristics she possesses. She exclaimed that she has the ability to keep her head clear and follow through with her duties, and that she is,” that person that can see the path to the end.” She explained that she has the ability to remain clear-headed and on-task, and that she can detach herself just enough to avoid getting tangled up in emotions. She continued, “I have a little trouble understanding why everybody’s brain doesn’t work like that, everybody thinks that clearly, people are a little more fluffy than me.” Jen made a distinction between the ways in which her brain functions in opposition to those who operate differently from her, signifying that others do not intrinsically possess what it takes to be a hospice worker. She is the chameleon that Anne described as she has the ability to navigate her multiple roles as educator, emotional supporter, and logical, clear-headed listener; managing them all in a way that puts her patients first.

My interviewees asserted that to be successful in hospice workers must dedicate themselves fully to their patients and their patients’ families. Having this passion and selflessness is part of the calling and natural inclination to do this job well. Sam, the only male member of my sample, was the only person I interviewed who stumbled upon hospice randomly. He first worked in maintenance in a hospice facility and then, when moving to a new city, he started applying to jobs. One of these positions was at a hospice, something he never thought he would get hired for. Before becoming a CNA and working in maintenance he always thought that hospice workers “had to be the best of the best.” After entering the medical field, Sam realized that, more than in any job he had worked before, hospice workers are people who, “will go the extra mile every day for years and give up so much of their own life and their own time for other people.” Hospice is where these workers are meant to be and they prove this through their devotion for their work.

Rachel also spoke about why people want to enter into the field when she said, “its definitely not a job where you’re gonna gain a lot of glory [laughs] per say. You don’t go into it for that, you know, you go into it at a really ground level of wanting to make a difference and caring.” Hospice workers are drawn to committing their lives to this cause they feel is worthy in spite of outsiders’ misconceptions of their field and, more generally, death and the dying process. Anne agreed, “Yeah, some people go into the field though and they just want it for the money or not that it’s great but they don’t go into it cuz it’s something inner driven, they’re probably the ones that suck [laughs].” Even after going through nursing school or CNA training, hospice is not a branch of the medical world where one can simply enter and excel. People are brought to this work through inner drive and the belief that it is their duty, whereas my interviewees felt that other nursing careers may not have this same extreme pull.

“It’s our honor to walk with them through this journey, and it is a huge honor”

In addition to feeling rewarded by having the ability to help patients by putting them first, many of my interviewees expressed that they felt honored to work in hospice and to have the opportunity and ability to help patients and their families during the dying process, a special and private time. Mary spoke about the most rewarding aspect of her work:

> You know, knowing that I'm bringing them relief, one of the, a daughter said, 'I am so relieved that were doing this.' She said, 'Now maybe I can sleep all night because I know he's got this extra care.' And to me it was like, that's all I need, that's all I need**.** I know, I just, it's that sense of bringing relief so patients and families know they're not alone in this journey, that there are people who can walk with them. I mean that's one of our, we have core principles, and its our honor to walk with them through this journey, and it is a huge honor

Mary not only felt rewarded knowing that she made a significant and meaningful impact in her patients' and their families' lives, but she also described her ability to do this work and be a part of the dying process as an honor. She felt important being able to provide comfort and support for families and to make sure that they were not alone during this time. By framing hospice work in this way Mary has also framed being involved in the dying process in a new light. While most Americans fear death and avoid anything related to it, Mary and others I interviewed explained that it is a special time in life that many do not get the chance to be a part of. They view this opportunity as a gift, something that they feel lucky to be involved with.

Lucy felt similarly to Mary, feeling honored to be able to do hospice work and do it well. A CNA working in hospice for two years, Lucy explained why she was surprised that she could do the work that hospice entailed. She said, "It was scary and I didn't think I'd ever be able to wash a person who had passed, you know, touch them or anything like that and when I found that I could and that it was an honor to do so I was like well maybe I could do this for real," and she later continued, "but to be there when somebody takes their last breath or to take care of their body after they've gone, that is pretty amazing and awesome and not everybody can do it, not everybody wants to do it." Lucy emphasized the honor she felt it was to have the capacity to work in hospice successfully. She felt proud that she could be a part of the death process and do things for the patient and family that many people would never think about doing, such as giving a death bath after a patient had passed. Her willingness and capability to perform tasks like these brought her pride and made her feel valued.

Anne echoed these points as well. When I asked how it made her feel that she was able to be the person who helps people exit this world she responded, “Honored. I do, I like being that person. I’m good at what I do so I like knowing that I can give a lot to the patient and family and help them feel more comfortable about that part of life that people are so weird and uncomfortable about.” Anne felt validated in knowing that she was capable of giving her clients what they needed, and also knowing that she was successful in her career. She also acknowledged that the subject of her work is one that the general population is avoidant and uneasy about, making her one of the few people to take on what society views as a challenging and dirty task. She expressed that this is not something that everyone can do or wants to do, and like Lucy that also gave her a sense of pride.

Working in hospice has also impacted the ways in which many hospice workers in my sample view the often-stigmatized life process of death. Unlike others outside of this field who think of dying as a depressing and morbid time, most of my interviewees framed this process as special. Sam stated, “I think it’s a beautiful process people dying…cuz I mean being born is a really, a really neat thing. And living is a really neat thing. And dying is really beautiful too because I have yet to see a person who has died who has not had somebody that’s not there to like walk them through.” When patients die with hospice they have a whole staff of people who have devoted themselves fully to ensuring that they die in the way they wish, allowing this process that is commonly avoided as something special. Seeing this play out in their occupational experiences allowed my interviewees to explain this final stage of life as sacred, and their ability to be a part of it is a gift. Lauren also communicated this sentiment while speaking to me about her feelings regarding being there during the dying process. She uttered through tears, "I mean, you only, you're only born once, you only die once, it's pretty special, yup, so yeah." Lauren drew a line connecting the beginning and end of life, establishing that she conceptualizes each of these two processes as the counterpart to the other. One does not hold more weight than the other, and both are intimate and special times that should be cherished. Yet most people are clouded by the thought that death is the dark end, unable to see the beauty it, as well as birth, holds. Working in hospice and spending time with the dying allows workers like Lauren and my other interviewees to see death in this light.

Anne reflected Lauren when she compared the process of death to the process of birth, a stage in life that society typically views as joyous and celebratory:

> There's nurses who do labor and delivery and they say it's the same thing: it's an honor and a gift to be there when that person enters the world and that baby comes into the world and the mama has the baby and all that. It's the same way for me but it's exiting. It's just, it's [a] very intimate and scary time for a lot of people so it's nice to be that person to comfort them and help their loved one go onto another part of life which is death

Anne spoke about how this time of life is private and terrifying for most people, and again brought up how honored she felt to be someone with the ability to help these people through this natural process. By describing it in this way, however, she also framed death as incredibly significant and extraordinary. In the way society views the process of birth she views the process of death, seeing that it is another powerful moment in the life cycle that should be treated as such.

The hospice workers I interviewed not only thought of death as a significant and special time in life, but they also felt honored to get the chance to gain insights about life from working with those in their final stages. Mary spoke about what parts of her work she shares with her husband, and how these things impact the way she not only views the process of death but also her own life:

> I will share with him things that impact me when I maybe talked to a family or something happened and usually its something that reminds me how short our life is and how insignificant things that used to be significant aren't anymore because every single day that I get to go to work I get to be reminded of how lucky I am, and it's a huge gift

The members of my sample seemed to have an insight into the art of living that one could only obtain by working with the dying and experiencing what goes on in the end-of-life. Mary described how this job has given her the chance to examine what is important in her life and has allowed her to value every moment because people tend to focus on the wrong things in the short time they have. Mary and her fellow hospice workers that I interviewed take away lessons they can implement in their own lives from their time supporting their patients in their last moments on Earth. When Emily started working in hospice care she was going through a difficult time in her own life, and she described beginning a career in this field as life altering, helping her establish what was important to her:

> What it did for me was that it made me realize that what my priorities needed to be in my own life; that I was I was doing things in my personal life that were not in my best interest both emotionally and physically for my own health, and that I needed to stop doing some of those things, reprioritize my own priorities, and get centered better in my own life and focus on my own physical and emotional

> health more, and really look at what my priorities were in life you know, my children, my own heath, my family, being centered

Working in hospice and being surrounded by people facing end-of-life questions and decisions pushed Emily to reframe the way she viewed her own life, and forced her to make serious changes that would help her move forward and improve it. Before coming to hospice Emily had an extensive career in the medical world, starting in psychiatry and chemical dependency and moving through positions in blood banking and developing programs for people with congestive heart failure. Yet her foray into hospice is what opened her eyes to the problems she was dealing with personally, changing her perspective and allowing her to progress.

Lauren discussed the idea of putting things into perspective, talking about how excited she was when her team won the World Series but realizing that it did not matter in the grand scheme of things as it was just a game at the end of the day. She stated, "I wish people would get in that mindset way earlier in life rather than like waiting until a loved one dies or waiting to be old or whatever, you know, I wish everybody valued life like that, but we don't, we just go around and do our thing and you know." For Lauren, having the opportunity to be with people in their last days has allowed her to make the most out of her own life. Death is special because it gives the gift of clarity to the living, but only to the living that have the ability to deal with and accept it.

CONCLUSION

In this thesis I found that hospice workers contextualize their work as being more rewarding than other areas of treatment through a patient driven practice that empowers the dying to have agency over their end-of-life experiences. They frame their work as either a calling or a natural ability, seeing their work as an honor and a source of insight into both life and death.

Hospice workers rationalize their abilities to do their work as a calling or natural inclination, highlighting that this is work that cannot be taught. When entering hospice as an employee there is no additional emotional training incoming workers are required to undergo. In addition to drawing on their past experiences in other treatment fields successful hospice workers posses the innate skills that allow them to balance intense emotions while remaining logical and clear-headed, always putting their patients' interests first. Hochschild (1979) defined the term "feeling rules" to describe the normalized way to express emotions prescribed to all spaces and types of interaction. Hospice is an emotionally charged environment, and workers are expected to show genuine compassion for their clients. Yet there is also an invisible boundary workers must not cross so as not to become a burden to their patients and their patients' families. This emotion work, while exhausting, comes naturally to hospice workers who succeed in their careers.

Workers in this caring field also rely on their clients' reactions to them when building their own self-image. Humans exist in a social world, and therefore internalize outsiders' perceptions when making conclusions about themselves. In hospice, workers feel valued because of the positive responses they receive from their patients and their patients' families. Yet my findings push this idea further. It is not only the praise hospice workers receive that gratifies them, but the fact that they have the ability to empower their patients to take agency over their end-of-life experiences. This reward is two fold in that hospice workers feel accomplished to be able to gift their patients, who have been silenced and ignored, their voices back.

Giving hospice patients agency in deciding how they want to live out their last moments on Earth is significant because the dying and diseased are populations that have typically been devalued and silenced throughout history. There are norms and expectations to live up to dying in America, where doctors push tests and treatments in order to prolong life in most ways possible. While patients technically have the right to tune this out, the pull is strong to succumb to medical authority.

Yet hospice is a place where death is accepted as the final outcome, providing care in direct opposition to the medical standards established for end-of-life. They provide a service that empowers the dying instead of leaving them ignored and distraught. Hospice workers are able to become the supportive and selfless professionals that my interviewees presented themselves to be by always putting their patients first. Americans' fear and avoidance of death, however, creates a cloud of false perceptions and stigmatization that surround hospice work. Until society becomes more comfortable with these subjects this field of work, and death and dying, will continue to be misrepresented and misunderstood.

Working with the dying gives hospice workers the clarity to accept death as inevitable. Americans must welcome hospice workers' experiences with the dying and detach the stigmatizations they associate with death in order to gain the insights into life that hospice workers have. Lifting the veil that has kept these stories and taboos hidden has the potential to improve how people live their lives in this country *before* they are forced to confront death in any way. Listening to hospice workers' voices will also serve as a source of power to push back against the medicalization of death and the disempowerment of the critically ill and dying. It is important that this work does not continue to be ignored.

Limitations

This study was not without limitations. Because I worked with a self-selecting sample I could not control who my participants would be, and all those willing to take part in my study presented as white while only one out ten identified as male. Due to the nature of this process I was unable to delve into the many implications that these two factors may have brought to the surface. In particular to this study, because there was one male outlier, I sensed there to be a disparity regarding outsiders' perceptions of males and females and their identities as hospice workers. Sam, my only male interviewee, expressed a viewpoint contested by my nine other subjects pertaining to being praised for working in hospice. Unfortunately, however, I did not have enough data to deeply explore this issue further.

Future Research

The findings explained above led me to believe that outsiders' perceptions of hospice work may depend greatly on the gender of the worker. It is crucial to understand the impact that gender identity plays, especially in a field of work primarily staffed by females. Examining the identity-construction of a stigmatized and misunderstood job without including gender as a variable runs the risk of ignoring a factor that could be significant in the creation of outsiders' perceptions. The same can be said of race, although with the makeup of my sample I was unable to make any significant projections about this.

While it may be difficult to conduct, I strongly suggest future research on patients' experiences in hospice care as this would foster an understanding of the dynamics at play between them and the workers. This study only examines the ways that patient empowerment impacted the workers, but does not venture to hear from the patients themselves. Focusing on these patients and how they respond to this alternative branch of medicine would shed light on their lived experiences dying in a death phobic and highly medicalized society. Furthermore, it would allow the researcher to understand the complete dynamic between hospice worker and patient during the dying process.

REFERENCES

Angela Hospice. What is Hospice? Retrieved December 15, 2016 (http://www.angelahospice.org/what-is-hospice-care/)

Ashforth, Blake. E., and Glen E. Kreiner. 1999. "'How Can you Do it?': Dirty Work and the Challenge of Constructing a Positive Identity." *Academy of Management Review* 24 (3): 413-434

Cain, Cindy L. 2012. "Integrating Dark Humor and Compassion: Identities and Presentations of Self in the Front and Back Regions of Hospice." *Journal of Contemporary Ethnography* 41 (6): 668-694.

Charmaz, Kathy. 2006. "Gathering Rich Data." 13-41 in *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage Publications Limited.

Charmaz, Kathy. 1980. *The Social Reality of Death.* Reading, MA: Addison-Wesley Publishing Company.

Conrad, Peter. 1992. "Medicalization and Social Control." *Annual Review of Sociology* 18: 209-232.

Conrad, Peter., and Joseph Schneider. 1980. Deviance and Medicalization: From Badness to Sickness. St. Louis: Mosby.

Cooley, Charles Horton. 1983. "Looking-Glass Self." Pp 183-185 in *Human Nature and the Social Order*, New Brunswick, NJ: Transaction Publishers

Cooper, Cary L. and Simon Mitchell. 1990. "Nursing the Critically Ill and Dying." *Human Relations* 43 (4): 297-311

Douglas, Mary. 1966. "Secular Defilement." 29-40 in *Purity and Danger: An Analysis of the Concepts of Pollution and Taboo.* London: Routledge & Kegan Paul Limited.

Gini, Al. 1998. "Work, Identity and Self: How We are Formed by the Work We Do." *Journal of Business Ethics* 17: 707-714.

Hochschild, Arlie Russell. 1979. "Emotion Work, Feeling Rules, and Social Structure." *American Journal of Sociology* 85 (3): 551-575

Hughes, Everett. C. (1984). “Work and Self.” Pp 338-347 in The Sociological Eye, New Brunswick, NJ: Transaction Inc.

Huppatz, Kate. 2010. “Respectability and the Paid Caring Occupations: An Empirical Investigation of Normality, Morality, Impression, Management, Esteem in Nursing, and Social Work.” *Health Sociology Review* 19 (1): 73-85.

James, Nicky. 1989. “Emotional Labor: Skill and Work in the Social Regulation of Feelings.” *Sociological Review* 37 (1): 15-42.

Lawton, Julia. 1998. “Contemporary Hospice Care: The Sequestration of the Unbounded Body and ‘Dirty Dying.’” *Sociology of Health and Illness* 20 (2): 121-143.

McNamara, Beverly., Charles Waddell, and Margaret Colvin. 1995. “Threats to the Good Death: the Cultural Context of Stress and Coping Among Hospice Nurses.” *Sociology of Health and Illness* 17 (2): 222-244.

Meldgaard Hansen, Agnete. 2016. “Rehabilitative Bodywork: Cleaning up the Dirty Work of Homecare.” *Sociology of Health and Illness* 38 (7): 1092-1105.

Pew Research Center 2013. Views on End-of-life Medical Treatments. Retrieved December 18, 2016 (http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/)

Quinn-Lee, Lisa., Leah Olson-Mcbride, and April Unterberger. 2014. “Burnout and Death Anxiety in Hospice Social Workers.” *Journal of Social Work in End-of-Life & Palliative Care* 10: 219-239.

Schwalbe, Michael. L. 1988. “Sources of Self-Esteem in Work.” *Work and Occupations* 15 (1): 24-35.

Seymour, Jane. 1999. “Revisiting Medicalization and “Natural’ Death.” *Social Science & Medicine* 49: 691-704.

Seymour, Jane. 2000. “Negotiating Natural Death in Intensive Care.” *Social Science & Medicine* 51: 1241-1252.

Stacey, Clare L. “Finding Dignity in Dirty Work: The Constraints and Rewards of Low-Wage Home Care Labor.” *Sociology of Health and Illness* 27 (6): 831-854.

Thompson, William E,. 1990. “Handling the Stigma of Handling the Dead: Morticians and Funeral Directors.” *Deviant Behavior: An Interdisciplinary Journal* 12: 403-429.

Tracy, Sarah J., Karen K. Myers., and Clifton W. Scott. 2006. "Cracking Jokes and Crafting Selves: Sensemaking and Identity Management Among Human Service Workers." *Communication Monographs* 73 (3): 283-308.

Twigg, Julia. 2000. "Carework as Emotional Labor." Pp160-178 in *Bathing-the Body and Community Care*, Psychology Press.

Twigg, Julia. 2000. "Carework as Bodywork." Pp137-159 in *Bathing-the Body and community Care*, Psychology Press.

White, Zachary M., and Cristina M. Gilstrap. 2016. "Inside Patients' Homes: A Metaphorical Analysis of Home Hospice Nurses' Experiences Working with Dying Patients." *OMEGA-Journal of Death and Dying* 71 (4): 302-315.

Zweig, Steven C., and Debra Parker Oliver. 2009. "Returning from the Total Institution to a Home Environment: A Journey for Birthing and Dying." *Journal of Housing for the Elderly* 23: 116-129

APPENDIX A:

Interview Guide:

Entering Medical Field/ Hospice Work:

x. Describe your position at Synergy Hospice Care.

1. Tell me about why you decided to enter the medical field (Once I know specific title I will use this).
   Probe: How long did you know you wanted to work in this field? When did you first consider becoming a nurse? Did you have any family members or close friends who worked in the field? What did you think about medical professionals before becoming one yourself?

2. Tell me about your first job working in the medical field (nursing).
   Probe: What were your responsibilities? What did you like about this job? What didn't you like about this job? Why did you decide to take this job?

3. How did you come to work in hospice care?
   Probe: Had you considered working in hospice care before? Did you have an experience that brought you to this line of work? Did you know anyone who had worked in hospice care before you entered the field? What did you know about hospice work before taking this job?

4. Tell me about your first days on the job.
   Probe: What did you do? How did you feel about it? What did you tell your friends and family about it?

5. Did you talk to anyone about your job when you were first starting?
   Probe: Whom did you talk to? How did you describe your work? How did they respond? How did you feel about their response?

6. Do your friends and family understand why you do the work that you do?
   Probe: How does that make you feel?

7. Did you have to go through additional training when you first started working in hospice care?
   Probe: What did it entail? How did you feel about what you learned?

7. What was the first thing you can remember that surprised you about working in hospice care?
   Probe: How did you feel about this? How did you respond?

8. How did your coworkers treat you when you first started working in hospice?
   Probe: How did this make you feel?

9. Were you considering working in any other fields before you started working in hospice care?
   Probe: What field? Why?

10. Tell me about the first experiences you had working directly with patients?
    Probe: How did it make you feel? What did you learn from it?

11. Tell me about the first interactions you had working with patients' families? .
    Probe: How did it make you feel? What did you learn from it?

12. How does working in hospice care compare to your expectations of what it would be like?
    Probe: Were you disappointed? Surprised?

Experiences in Work:

1. Walk me through a typical day at work (From the very beginning to the very end)

2. What are your day-to-day duties?
   Probe: Do these change? Have you always been responsible for these tasks?

3. Where does most of your work take place?
   Probe: What duties are performed where? Why?

4. Tell me what a typical patient stay is like?
   Probe: Is this common?

5. Can you describe what happens when a patient passes on?
   Probe: What are your responsibilities? How do you react and respond in these situations?

6. How do patients typically respond to you?
   Probe: How do they treat you? How does this make you feel?

7. Tell me about a typical interaction with a patient's family?
   Probe: Describe the process. How does the family treat you? How do you treat the family?

7. What is your favorite part about working with families?

8. Describe how dealing with a patient's family makes you feel.
Probe: Why?

9. Tell me about a positive experience at work that you can remember.
Probe: What happened? Who participated in this experience? Where did this happen? How did you feel about it afterwards?

10. Tell me about a negative experience at work that you can remember.
Probe: What happened? Who participated in this experience? Where did this happen? How did you feel about it afterwards?

13. What is the most rewarding part of your job?

14. What is the most challenging part of your job?

15. Can you think of a time when you felt emotional at work?
Probe: How did you act in this situation? How did others respond to your reaction?

15. How do you deal with these emotions in the workplace?
Probe: What techniques do you use?

16. Describe your transition from work to home life.

17. When people ask you about your work, what do you tell them?
Probe: Do you think it is important for others to know what you do for a living?

18. How does working in hospice care compare to other jobs you have had in the medical field?
Probe: How is it "better?" How is it "worse?"

18. How do you think people who do not know about hospice see you and the work you do?
Probe: Why? How does that make you feel?

19. How do you deal with stress in the workplace?

20. What are your views on the current medical system, especially how it relates to dealing with death and dying?

20. What advice would you give to nurses just starting out in hospice work?

21. What do you wish people understood most about hospice?

Views on Death and Dying:

1. How did you view the dying process before you started working in hospice?
   Probe: Did hospice work influence this view? Did your views lead you to a career in hospice work?

2. What are the most important lessons you have learned while working in hospice care?
   Probe: Do you think you could have learned these lessons somewhere else?

3. What are your views on Proposition 106, The Colorado End-of-Life Options Act?
   Probe: Why do you feel this way?

4. How comfortable are you with the idea of death?
   Probe: Has working in hospice influenced this view?

Conclusions:

1. Do you have advice to give to people who may be interested in working in hospice?
2. Is there anything we have not touched upon or anything that we did not spend enough time related to your work in hospice that you would like to talk about now?
3. Do you have any suggestions of what I can ask in my future interviews?
4. Do you have any questions for me?
5. Can you just take a moment to reflect freely on your work and anything about hospice care that is important to you.

Demographic Questions:

1. How many years have you worked in hospice?
2. What were your jobs prior to working in hospice?
3. What year were you born in?
4. If any, what are your religious affiliations?
5. What is the highest degree you hold?