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Dying Today: Perspectives of the Modern Hospice Worker

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ABSTRACT

From a sociological standpoint, death is relatively difficult to research. While some individuals may describe near-death experiences, the actual act of death cannot be fully known to the living. The purpose of this study is to gain insight into the nature of death and dying in the United States today. This research examines the perspective of modern hospice workers. These individuals work near death on a regular basis and therefore have a privileged understanding of what death is like in US society today. Data consist of ten in-depth interviews with hospice/ palliative-care workers in the Midwestern United States. Respondents were asked questions aimed at gathering data in several distinct areas. The first of these was to outline the modern death context, or social context which encompasses the behaviors and attitudes about death found in society at a given time. The next area of inquiry was on the emotion work required to work near death as well as the emotional labor required to work with individuals and their loved ones in providing end-of-life care. The final area of the findings focused on how the understandings of the respondents changed as they became familiar with the notion of death. Their responses suggest that though the modern death context may not offer extensive experience with death, and that individuals may overcome this unfamiliarity by experiencing death with some frequency. Furthermore, this achieved familiarity seems to help the individual accept death and therefore accept their own mortality.

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This thesis has been examined and approved by the following members of the thesis committee.

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I.

Introduction

"Death is, after all, one of the characteristic features of human existence, and the people of any society must find the means to deal with this recurring crisis" (Glaser and Strauss 1965:1).

What is the nature of death and dying in the United States today? This simple question can be very difficult to answer. Symbolic interactionism posits that individuals create and negotiate the meaning of social objects (people, things, actions) through interaction with others in a shared social context. Therefore, to understand modern death, both the context and the interaction within it need investigating. From the interactionist perspective, the social context in which one dies is not a static environment. This context is constantly created, recreated and altered as social members interact within the context, as well as with social forces contained within it. These members are informed and influenced by forces such as normative practices and institutional pressures. Thus, it is the social context which provides the resources from which the individual constructs meaning. This is why the universal act of dying may be experienced very differently from one social context to the next.

Dying in the United States today is, indeed, very different from previous times. Medical advances have prolonged life considerably. As society has changed with modernity, so has the way people live and die. Sociologists interested in death have noted that the modern death

context is characterized by an absence of death from public space and thus the everyday experience of the individual. Death is described as hidden (Walters 1991) or sequestered (Mellor and Schilling 1993) from society and its members. With death largely out of sight to the modern individual, the dying experience occupies a smaller amount of social awareness in society today. Sequestering death to specific institutions, such the hospital, and to specific societal members, such as the mortician, leads to a sequestration of thought and meaning surrounding the topic. As death is so neatly tucked away out of sight, the individual has few chances to interact with the dying experience and therefore will have limited resources from which to construct death-meanings. He or she may then be forced to assemble their meanings from a small number of personal experiences and from institutions such as various forms of media. If our death context is marked by an unfamiliarity with death, how then can we explore what is like to die in the US today? To answer this question, we must look to those privileged individuals who maintain close proximity to the dying with some regularity.

Standpoint theory (Harding 2004) posits that all members of society occupy a certain standpoint with a unique perspective on the context in which they live. Furthermore, those who occupy standpoints which are marginalized within a given context may have deeper insight into that social experience than those looking out from within the dominant discourse. This is why I have chosen the hospice worker as the standpoint I will explore. Though the modern dying is typified by increased privatization and medicalization, not all modern death occurs in this way. It should be noted that many death experiences run counter to these tendencies, as they occur in settings that deviate from normative practices. Hospice is one such setting. The hospice approach to dying is inherently different than the dominant medical discourse. While doctors often view death as an enemy or failure, the hospice approach views death as a natural

occurrence that requires multiple forms of support (Clark 2000). As the hospice approach is not in line with the dominant social discourse on death and dying, those who perceive death from the hospice standpoint provide insight into the modern death context at large. In other words, they do things differently and thus have an awareness of how their approach differs from the medical approach.

Though hospice practices are rooted in traditions dating far back into the past, the modern approach is mostly credited to Cicely Saunders, a British nurse (Clark 2000). Her experiences led her to a notion of total pain, which describes psychological and spiritual pain as well as physical sensations of discomfort. She noted that the primary medical approach to death was to treat the illness instead of treating the individual. Thus, her hospice efforts were aimed at providing palliative care for the body as well as spiritual and psychological support. Often, this meant providing support for the family as well as the dying person. The notion of total care has traveled across the Atlantic and has been growing as an approach to care for serious illness in the United States ever since.

Providing end-of-life care is no simple matter. For the worker to be successful, he or she must offer care that is individualized to the person being cared for. Within the layers of the services provided is the concept of emotion management (Hochschild 1983). This term refers to the ways in which members of society manage their emotions and those of others to bring them into accordance with perceived societal expectations. The PCWs facilitate care for people with serious illness. This requires the ability to manage both their emotions in the face of intimate and intense moments near the end of life. Interactionist interest in emotions has increased in recent decades and the hospice worker provides a unique opportunity to explore these concepts. Hochschild (1983) has shown that certain forms of employment require emotional labor,

demanding that employees manage their emotions in specific ways, usually to gain a favorable response from those they interact with. Surely the hospice worker is involved in this sort of emotion management. Furthermore, the ability to be comfortable with dying individuals is not a skill this society readily provides. In order to care for the dying, the hospice worker must also manage his or her own emotions regarding death. The examination of the transition from the normative unfamiliarity with death to managing death as a professional will provide insight into both the modern death context and the emotion work that is required within care giving interactions. This study will explore the role emotion plays in providing end-of-life care and the way it is managed by those who perform the work

From a sociological standpoint, the modern hospice worker provides an extremely intriguing perspective due to the unique standpoint these individuals occupy. The hospice worker sits at the intersection of a variety of crossroads within the modern death context. Working near death provides individuals with a unique experience. Considering the limited visibility of death in modern society, dying is a topic that most people are able to consider, or not, at their relative leisure. Those who interact with the dying and see the dead regularly do not have this freedom and are forced to find ways to manage death as an everyday experience. As individuals living within this context, their familiarity with death is atypical. Furthermore, we can assume they were not born into this position, so the process by which they acquired this rare familiarity is of interest. Working with the dying places the PCW in a small group of death specialists, alongside others who work in various medical, mortuary and religious institutions. Their experience within this group is also atypical, as their focus is on the dying individual and their family, not the illness within them or the burial rites of the deceased. Furthermore, they bridge the gap between pre-modern and modern approaches to dying. Though they currently

work and provide care in the modern context, the origins of their approach originate in times when death was understood very differently. For these reasons, the standpoint of the hospice worker is invaluable for assessing the modern death context.

In this paper, I explore death in society from the perspective of modern hospice worker. I begin by examining the share social context in which death in society takes place.   Following this, I explore the micro interaction which takes place within that context. The first of these sections focuses on the experience of gaining familiarity with death and how that familiarity affects the death understandings of the familiar individuals. I close with a discussion of the emotion management performed by the respondents as they encounter death regularly through the course of their employment.

II.

Literature Review

Modern Death

"Most deaths now occur not among the young but among the old. Death, thus postponed, is taking on new meanings for both the individual and society." (Riley 1983: 191)

Describing the modern death context requires a discussion of how it is different from previous forms. Lofland (1978:12) notes six characteristics of pre-modern dying which are now absent in our current society, including "minimal medical technology, late detection of fatality-producing conditions, simple definition of death, high incidence of acute disease, frequent fatality from injury and passivity towards death". As such, modern death is very different for those living now than it was for those living even one hundred years ago. Pre-modern death, as described by Lofland, took place much more visibly throughout society and was common from even small injuries. Pre-modern dying was also not primarily reserved for the elderly, as it is in the modern context. Death was a taken-for-granted experience in the pre-modern context which was viewed passively and accepted as a typical life experience. Aries (1974) agrees that death in pre-modern times was more readily accepted. He writes that as the social world in those times were "steeped in the supernatural"; death was accepted simply and without question. Without this familiarity to death in one's everyday experience, dying in modern conditions is much different. Lofland (1978) describes death within the modern context as being bureaucratic, informed by secular ideas and occurring much later in life. These characteristics combine to

normatively situate death in certain social positions, such as within the elderly population. As such, these characteristics also inform the normative understandings of modern death and dying for the members in a given society.

Writing from a constructionist perspective, De Vries (1981) relates death to birth, viewing both as "existence transitions". He argues that, as individuals construct meaning through social interactions, social context is important in defining how death is experienced, perceived and understood. He states that considerations of the death context should contain both the "immediate social location" as well the "larger historical setting" (De Vries 1981:1076). Furthermore, the increased bureaucratization of society noted by many scholars explains why the typical death setting has shifted from the home to the hospital. Due to this, De Vries is surprised that any remnants of traditional death practices, such as dying in one's home, persist today. The modern death context, where death is removed from our everyday experiences, is the historical setting which underlies the interaction which occurs within it. Though members of society may view their perspectives on death as natural and rational, the modern death context is largely the basis for their understandings.

Other scholars empirically explore the specific interactions within society which highlight the modern context. Glaser and Strauss (1965) note that most people now die in hospitals. As opposed to death itself, their study focuses on the social process of dying. To accomplish this, the authors examine dying through the interaction of the patients and hospital staff as they become aware of impending death. They discover a series of four forms of awareness management strategies. The first form is called *closed awareness*. In this awareness dynamic, the patient does not know that the medical staff believes they will die. The second form is named the *suspicion awareness*. In this model, the patient becomes increasingly aware a

sense that the staff believe they will die. This form is compared to a fencing match, as the patient goes on the offensive to obtain information from the defensive staff. The next form type is called *mutual pretense*. This dynamic describes when both know but pretend that they do not. The final awareness type is called *open awareness*. This form is typified by both patient and staff being aware and openly acknowledging this fact. Glaser and Strauss (1965) highlight the complex ways in which the modern context interacts with the modern individual. Aspects of modernity place the dying individual in the medical setting as well as inform the dynamics within it. Largely, these interaction dynamics are arranged with regard to the plentiful information obtained through modern medical technology. Though the doctor may know how to read the results of a blood-test, they may not be emotionally prepared to inform a person that their life is going to end sooner than they believed.

Mellor and Shilling (1993) further the discussion of how the individual copes with death within the current social context, a period they period of "high-modernity", a term they borrow from Giddens (1991). The authors describe three tenants of this time. The first of these is increased reflexive reordering of biographical narratives in the construction of self. With the aid of various professionals, individuals in this time period may learn to construct a favorable sense of who they are by focusing on certain life events over others. This is similar to the narrative work performed by transsexuals in creating and confirming a sense on "true self" to help transition from one gender to another (Mason-Schrock 1996). The second tenant is the shrinking of the scope of the sacred which includes both increased secularism and less social space for the sacred in general. Religious institutions no longer provide a certainty on which the individual can rely. They are forced to look elsewhere for answers as to the forces outside of their personhood. The third characteristic of the period of high-modernity is the increased

identification of the self with the body which is said to be tied to the lack of input from religious sources. Without the ability to identify the self with religious notions such as the eternal soul, the individual places more emphasis on the physical body to conceptualize a sense of self. This is also said to be influenced by increased pressures of consumerism in these times.

Mellor and Shilling (1993) describe how death in high modernity has become both sequestered and privatized. This results from stronger boundaries placed between living and dying bodies and professional specialization surrounding death. The authors note that interpreting the context in this way can place a negative connotation on the way death is managed. They refer to Bauman (1992) who understands these practices as simply another form of a survival strategy. Bauman argues that all societies must manage death in one way or another. Most religions used strategies of death-as-not-the-end to relieve societal death-anxiety. From this perspective, sequestering death can be seen as a way to focus on life in order to minimize fear of death. The focus on youth and beauty is another example of this, as it serves to counter and avoid death and old age. Mellor and Schilling (1993) conclude that it is not the lack of religion that is problematic within modern death; it is the lack of anything to take its place. Science has not offered an explanation for what takes place after death, leaving a void in which the individual must try to create meaning around death on their own. As death is relatively absent or hidden from society, experiences from which to draw meaning are rare. Without a way to situate one's understanding of their mortality, Mellor and Shilling (1993) believe death in modern society is often lonely and confusing.

Kellehear (2007) agrees that death in our current society is increasingly difficult for the individual. Here, he describes these difficulties in what he calls the Cosmopolitan Age. "Dying in this Cosmopolitan period increasingly produces deaths that are neither good nor well-managed

for anyone. People's attempt to prepare for death (as they did in farming communities for millennia) or to tame death through medical or other forms of professional care (as they did in cities for millennia) is frequently thwarted, distorted or simply denied(pg. 8)." Kellehear notes that the strategies of previous times no longer work for the modern individual. It is this context of modernity that I examine.

Modern Hospice/ Palliative Care Work

As previously stated, a primary goal of the hospice approach to end-of-life care is to address the psychological and spiritual needs as well as the physical. This notion rests on the logic that some death experiences are more preferable than others. What, then, is a good death? In an attempt to distill common characteristics to aid in palliative care practices, Kehl (2006:284) finds that a "good death" is characterized as being "fluid and highly individual". Among the most prevalent of the characteristics she found were the notion of "being in control, being comfortable, a sense of closure, affirmation of life, and trust in those providing care" (Kehl 2006:277).

Many scholars also note problematic issues within the hospice approach. Hart, Sainsbury and Short (1998) argue that the preferable death advocated for by the hospice approach is in fact a form of social control which ultimately limits the options for the dying individual. A major concern for the authors is how some patients may be deemed "bad" if they do not follow the experiences preferred by the hospice model. Others describe the way the American hospice movement has begun to shift from its original form. Bradshaw (1996) finds that the many hospices have become characterized by heavy bureaucratization which serves to make the work routine. She argues that the spiritual aspect of end-of-life-care has begun to suffer from the

medicalization of the field. This may not be surprising, as hospice care is surely influenced by the western medical model. Paradis and Cummings (1986) use the term "isomorphism" to describe the way in which hospices are becoming both more like other hospices as well as other health care organizations such as hospitals. Lawton (1998) views the hospice movement as an institution in which to hide the "unbounded body". She argues that as the dying are deviant in modern society; they must have a place in which to die that is out of sight, Hospice provides this, even if that place is the home of the individual. In this way, hospice can be understood as helping to maintain the social boundaries between the living and the dying instead of bringing the two closer together.

A final aspect of modern hospice work which pertains to this study is the way death is understood by the hospice worker. Payne, Dean and Kalus (1998) compare the stress experienced by emergency room nurses to that of the hospice worker. They found that the ER nurses experience much more stress when encountering death than do hospice workers. This is largely due to the way each approaches death. As hospice workers accept death, the stress surrounding it is minimized. Also, the hospice worker has greater opportunity to talk about their experiences with others. As the ER nurses were found to lack this from their peers, their stress levels were higher. This study indicates that the way in which death is framed plays a large role in how it is experienced. By providing an alternative to the normative hospital death, the hospice approach provides a framework for death as the culmination of life. This is why the death understandings of the hospice worker are of such interest to this study.

Emotion Management

Over the past few decades, symbolic interactionist inquiry has begun to examine the role

emotion's play in social interactions. Hochschild (1979) found that, like societal norms of behavior, "feeling rules" exist for how one should feel and the emotions one should display in a given situation. If one's emotions do not meet society's standards, the individual may try through a variety of methods to manage their emotions. Hothschild (1983) later noted that many forms of employment require the worker to present their emotional state in a certain way, though this may differ from how the individual actually feels. She called this process emotion labor. Simply stated, emotion work refers to managing one's own emotions for personal reasons while emotion labor involves managing one's emotions in order to perform a particular job. To bring one's presentation of self into accordance with job requirements, the emotional laborer must present their emotional state in a way that meets social expectations. As is the case with emotion work, this management can take place to varying degrees within the individual. To depict this, Hothschild distinguishes between "surface" and "deep acting". Surface acting requires the individual to outwardly present appropriate emotional displays, whether they feel that way internally or not. Deep acting takes place when the individual tries to bring their inner feelings into alignment with how they are supposed to behave on the surface, actively creating and changing their inner emotions.

The work of Smith and Kleinman (1989) provides a drastic example of how emotions are managed. They explain how medical students are informally taught to suppress feelings deemed inappropriate within the normative doctor-patient social dynamic. The students learn a variety of strategies through their schooling which allow them to compartmentalize their emotions towards those they treat. If a doctor were to react with disgust towards a diseased individual, this reaction might upset the patient. The emotion management techniques they learn seek to alleviate this distress. One example of the ways these students learn to manage their emotions is by using

medical terminology to redefine the unified individual as a series of disparate organs within the body. In other words, the medical students are taught to understand the body as something other than human. Though some students worry this may desensitize them towards others within personal interactions, these strategies are deemed necessary to gain the required detachment from future patients. It is this distance which allows a doctor to detach their emotions from the duties of their work, such as cutting into the human body. Though perhaps not as drastically as the medical students, the hospice worker must also learn to redefine their understandings towards those who are dying. I am interested in learning what, if any, emotion management techniques hospice workers employ to accomplish this redefinition of the dying person.

Presumably, the hospice worker must learn new ways of understanding death to handle being constantly near the dying. This process surely requires emotion work and emotion labor. Furthermore, emotion work is performed actively through the categorization of meaning. Thus, social experiences which are seemingly similar may require different emotion work strategies dependent on how they are understood by the individual in a given setting. Those who work near death may obtain social distance by using these strategies. In order to provide professional care for those who are dying, professionals must learn to compartmentalize their emotions. The death of a patient at work may therefore be understood differently than that of a family friend. By experiencing death with some regularity in a specific setting, emotion towards that type of death may become routine. The variety of ways these individuals are able to understand death highlights the socially constructed nature of emotion. As with the medical students, the way in which these individuals define their relationship to the dying is often central to understanding their emotions towards them.

III.

Methods

Gathering Respondents

This research was conducted in the winter of 2010/2011. My interest in aging and dying began long before this, while working at a somewhat unusual assisted-living home for the elderly in Boulder, Colorado. This home took a holistic view (focus on body, mind, and spirit) to aging and dying which they sometimes referred to as a modern-traditional approach. Within this approach, death was viewed as a sacred passage which signified the culmination of the person's life-course. End of life celebrations were common and the body of the deceased was often left in the home for three days, in accordance with the belief that the soul is in transition for a period of time after the death passage. Furthermore, whenever possible, the dying individuals were allowed to die in the home as opposed to a hospital setting. These sorts of actions were aimed at demystifying death by bringing it back into the everyday experience of residents, staff and loved ones. I soon noticed that these sorts of ideas seemed foreign to many people I spoke with about them, especially my peers. My friends could not believe I had actually touched a dead body. They assumed this would be a grotesque and morbid experience. I would explain that this was the body of someone who I had cared for and touched on a daily basis. Far from being unpleasant, caring for their remains was a sentimental act which aided in the grieving process. I was left to conclude that a lack of familiarity with the dying is what led my peers to make such assumptions about death. I began to wonder how such a fundamental human experience could

have become so exoticised to the people I spoke with.

This study explores the death-understandings and emotion management strategies of hospice workers. To do this, I used the grounded theory approach described by Charmaz (2006). This approach employs semi-structured interviews aimed at eliciting narrative answers from respondents. After gaining approval from both the Institutional Review Board of my University and the institution I was planning to draw my sample from, I began to search for respondents. This was not difficult as eight interviews were scheduled for my by the hospice organization themselves.

I interviewed individuals who worked in a relatively small hospice (Less than 50 employees) in a Midwestern city of around 50,000 people. Eight of the respondents were female and two were male. All participants were Caucasian. One of the respondents was born in Europe while the other nine were born in the United States. The participants held a variety of positions within the organization and thus interacted with the dying and their families in different ways. I will now give a brief description of the respondents and the work they perform. This will be followed by a quotation from each of their interviews.

Subject A (S-A) is a chaplain who works with the hospice organization. S-A's work lies in providing spiritual support for patients and their friends and family. S-A states, "I really believe it is a privilege to be invited into people's most intimate moments of their lives."

Subject B is a triage nurse with the hospice organization. S-B is largely responsible for the intake of patients. In this way, S-B is usually one of the first people an incoming patient will speak with. S-B states, "Many people have the perception that it's [hospice] a dark place to work, but I find that it's a place of peace, resolution, satisfaction and joy."

Subject C is a bereavement coordinator with the hospice team. S-C focuses on helping the families and friends of a patient work through the grief which follows a death passage. This is done by assessing how each person is coping with their loss. Those who are having trouble moving forward in their grief are offered greater assistance. S-C states, "It's hard to see their [friends and family] pain and wanting to make it better but you can't. You can support them and help them along but the pain is something that they have to carry."

Subject D is a volunteer coordinator with the hospice organization. S-D is responsible for the intake and training of all volunteers as well as scheduling them with patients. S-D says, "You hear of doctors telling patients that they is nothing else that they can do. This is incorrect. There is always something we can do."

Subject E is a direct care nurse who works with the hospice organization. S-E offers physical and medical support to the patients and assesses their condition. S-E states, "I really like it. To be able to work with a family from just coming to accept a diagnosis to seeing them through what I would call a good death. It's very rewarding."

Subject F is a doctor in a palliative care unit within a large hospital. S-F oversees the care in this unit and interacts with other branches of the hospital to bring the option of palliative care to a variety of patients. S-F states, "I meet people every day who are dying and it's no surprise to them. Why then is it to the rest of us?"

Subject G is a nurse who works closely with S-F in the palliative care unit. S-G assists in his work and provides support similar to a direct care hospice nurse. S-G says, "We [in society] have a lot to learn and palliative care is one of the areas that is working to encourage this awareness."

Subject H is a social worker with the hospice organization. S-H helps guide the patients and their families through the hospice process and insures that they receive the resources they need when possible. S-H says, "Support for the dying is changing in that there is now concern for more than just the physical symptoms of being ill."

Subject I is an RN case manager with the hospice team. S-I oversees case files and insures proper care and documentation. S-I states, "More education about death is needed. Right now, we could help more people if we could just get them [into hospice care]."

Subject J is a quality and performance improvement nurse who works with the hospice organization. S-J monitors documentation as well as making sure that all policies and regulations are being followed. S-J says, "Often there is a lot of unnecessary harm near the time of death. It's a bad experience for many people and it doesn't need to be. That is why education is so important."

Eight of the respondents worked together in a single hospice organization. The other two individuals, S-F and S-G, worked in the palliative care unit of a nearby hospital. Though hospice and palliative care are considered separate concepts in the modern death context, the services offered by hospice can still be considered palliative care. While palliative care units and hospice units exist side by side in society today, both approaches can be classified as providing palliative care. In other words, the institution of hospice as it exists in the US today provides a type of palliative care. In order to contain all of the respondents within a single title, I will use the term palliative care worker (PCW) to describe all of those who participated in this research. Though only two of the respondents actually work in a palliative care unit of a hospital (the other eight working in hospice), all ten of the respondents provide services that fall under the heading of palliative care. The interviews took place in the office in which the respondents worked and

were recorded and transcribed in full. All respondents were asked to sign a consent form which outlined the nature of the research as well as some of the possible harms associated with their participation. All data is stored in a secure file on my home computer. The confidentiality of the respondents was maintained through the use of pseudonyms in the transcripts.

Data Analysis

The grounded approach allows themes and topics to emerge from the understandings of the respondents in their own words. In this way, the researcher develops and explores themes from one interview to the next (Charmaz 2006). As such, data collection and data analysis occurred simultaneously and are intertwined with one another. The in-depth interviews followed a semi structured interview schedule which focused on the subsequent research questions. As themes emerge, they were explored in subsequent interviews. Beginning with the transcript from the first interview, each line was coded for relevant data. This allowed the response data to be sorted and more easily compared while still being represented by the ideas of the respondents. The most prevalent of these codes were noted and discussed in memos. These memos were used to gather themes and organize the response data as well as guide subsequent interviews. The use of codes and memos also allowed the data to be moved gradually from the actual transcripts to more conceptual levels. By using the constant comparative method advocated by Charmaz (2006), these memos were expanded upon to include data from as many of the respondents as could be applied. The strongest and most prevalent themes have been organized into the findings section.

Research Questions

To explore modern death, I chose the standpoint of the hospice worker. This social position offers insight into both the nature of modern death and the interactions surrounding end-of-life, which take place within the modern context. Of primary interest to my research is the construction of death meanings and the emotion management techniques which are used while providing end-of-life care.

Primarily, the questions I asked investigate the modern death context and explore the death-meanings of those who live within it. As the modern death context informs how death is perceived and conceptualized, these meanings offer insight into the context as a whole. Central to this inquiry is an examination of the processes of meaning construction around death in the modern context; I explore the transition of going from a normative member of society with limited death experience to becoming a death specialist. In the findings section, I explain what death definitions are created and altered as one becomes more familiar with the dying process. Furthermore, I called on the hospice standpoint to shed light on aspects of the modern death context such as the dominant medical model and other institutions which hold authority over death. My findings suggest that the modern death context is typified by unfamiliarity with death. This tendency is countered by the respondents, who see death often and have gained familiarity with the process. These questions provide the contextual backdrop for the specific interactions which take place within it.

To explore interaction within the modern death context, I examined the emotion management techniques used by hospice workers. This inquiry focused on both the emotion

work performed personally by the hospice worker as well as the emotional labor demands of performing their job. The respondents note that it because working near death can be emotionally trying; they have a variety of techniques aimed at supporting their emotional well-being. In particular, they describe an ideal emotional state for providing end-of-life care and the strategies they use to maintain that dynamic. This research expands on understandings of emotion labor by exploring emotion management in the extremely emotional setting of hospice work. The way in which the respondents meet the emotional demands of working near death highlights the utility of emotion management. This study also broadens understandings of how feeling rules are perceived and the types of emotion work strategies performed in response to them. As the deceased cannot share their death experiences with us, we are left to analyze the social interaction which surrounds this existence transition. The death understandings and emotion management techniques of the modern hospice worker provide an extremely rare glimpse into the nature of how death is managed in modern western society.

IV.

Findings

The findings section is divided into three chapters. The first of these is concerned with defining the modern death context. Here, the respondents describe normative understandings of death and entities they believe hold authority over death. This first portion closes with an assessment of this context by the respondents. The second findings chapter focuses on the process of gaining familiarity with death. This chapter describes how this process occurs and how it alters the PCWs understandings of death and dying. The final chapter describes the emotional aspect of providing palliative care. In this chapter, the respondents detail the demands of performing emotional labor as well as how they are able to protect themselves through emotion management.

THE MODERN DEATH CONTEXT

The modern death context (MDC) is comprised of the thoughts and interactions of those who move throughout it. This ever-changing swirl of social meaning surrounds these individuals and contextualizes their behavior. To say any one way of behaving within this context is "correct" makes little sense. A more accurate way to describe how a certain behavior fits into this social context is to place it on a conceptual spectrum which runs from normal in everyday life (within the context of postmodern, western society) to extremely deviant. The placement of a thought or action along this spectrum can be roughly decided by the response the acting individual receives from society. For example, guests visiting a funeral in the MDC might be

surprised to find the body of their deceased loved one positioned upright in a chair near the alter. The ensuing response to this scene might be a cue to anyone watching that a deviant or socially unusual act was occurring. While a variety of unusual behaviors exist in the MDC, this section begins with a description of those things, thoughts, and actions, which are deemed "normal" within the MDC. These taken-for-granted social meanings provide a baseline for assessing our current social context. Though never static, these normative understandings offer a partial snapshot of the context in its current form.

This section begins by describing normative death understandings from the perspective of the PCW. In general, these responses indicate a normative unfamiliarity with death in the United States. Discussion then turns to the social forces and institutions which the respondents describe as having authority over death. This description of the MDC will conclude with the respondents assessing the how death is managed in U.S. society today. Here, I outline their thoughts about certain trends and what their hopes for in the future.

Death Norms

The first step in describing the MDC is to define the normative understandings and behaviors within it. Within my interviews, I aimed to uncover how normative relationships with death are characterized, asking PCWs about their previous assumptions and experiences regarding death before entering the professional field as well as their perspective on society at large. S-I, a nurse within the organization, used these words, "I describe it [death] as something that was a part of life that didn't really affect me much, and the older I get the more I realize that it affects many, many people." Though death ultimately affects all humans, longer life spans

make considerations of death less imperative in the MDC. S-C, a bereavement coordinator who works primarily with families and loved ones of the patients, believed that considerations of death are somewhat absent in society. S-C said, "I think people think they will live forever so they don't accept death as reality, they deny it…" S-A, a chaplain with the organization, mentioned a belief that death does not fit well with some current lifestyles within the US. S-A states,

> And obviously we are kind of a materialistic society. We work our whole life to obtain these possessions and we sacrifice and then death comes and we have to leave all that. I think sometimes we wonder, gosh my life was wasted, I worked the whole time and now I have to leave it.

These responses provide a basis for the relationship society has with death in the MDC. When asked how people generally feel about death, the typical response was that they are fearful. S-A described society's relationship with death in this way. "For many people it's a scary experience. We don't want to talk about it and we don't want to hear about it." S-C agreed that many people have difficulty talking about death. "They don't want to face their mortality and they don't know how to talk about it. They often ask [when visiting a loved one close to death], what should I say?" This sentiment describes how an aversion to death can lead to an avoidance of it. S-A went on to say, "I often see our patients try to [talk about death with] their families or children, by saying maybe I should think about the service or maybe I should wear this dress and the kids say mom stop it, we don't want to talk about it, we don't want to hear it." From the PCW perspective, some of this fear seems to stem from not knowing what to expect. S-J, a quality assurance nurse, suggests, "I think for most people it's the fear of the unknown, not knowing how to do it correctly, in that death can be done in comfort and with

dignity and respect…" This leads many in society to remain unfamiliar and uncomfortable, perpetuating the marginalization of death experiences.

These responses support previous work on death (Lofland 1978; De Vries 1981; Walters 1991; Mellor and Schilling 1993) that suggest death is largely removed from the normative experience of the individual in the MDC, or at least more so than in previous eras. My findings suggest that, in the MDC, it is not uncommon to have a general unfamiliarity with death. In fact, this unfamiliarity appears to be a normative aspect of living in the MDC. Death is considered frightening and the mere thought of it is often rejected. Many believe that death does not pertain to them, at least not up until a certain point or age is reached. Furthermore, the notion of dying, as suggested, may run counter to some lifestyles and social trends which coexist with the MDC. Currently, it is normative that an individual will grow to adulthood without considerable experience with death. While this is true, many specific standpoints may provide experiences which run counter to this normative inexperience with death. Examples of these might be an individual in the medical field or armed forces. Though running counter to the normative experience, a variety of other types of death familiarity do exist within the MDC.

From the perspective of the PCW, this disconnection with death and dying in the MDC is a problem. While resources do exist for those nearing the end of their lives, many face death unsupported by those resources. S-B, a triage nurse, describes the situation this way:

> There is no direction or support [of care] so they [people in society] do feel like they are doing it [dying] alone, they may not even have a supportive care giving system and don't even know where the resources are to get help, so it can be a very difficult experience for some in the community.

As this unfamiliarity with death has become normative, being familiar with death may now be perceived as deviant. S-H, a social worker, related the way S-H's peers reacted to S-H

working near death as a "young" person. "My friends think it's weird that I can be around death and be comfortable with it, especially being relatively young for this line of work." Comfort with death is therefore deemed deviant, especially for the young. This speaks to the nature of the MDC. Those who work with people nearing death and who are comfortable doing so risk being characterized as deviant.

Authority over Death

When asked to describe what individuals, groups or institutions hold power and authority over death and dying in the United States today, the PCWs name a variety of entities and forces. The diversity of these answers from individuals who nearly all work in a single office offers insight into the complexity of the MDC. It seems there is no single authority over how we die. Instead, the MDC provides a combined influence which affects each person differently.

Several of the respondents said that it is the individual in question who is ultimately in control and maintains autonomy over choices of life and death. S-A explained:

> Well, it's largely an individual matter, we all experience death as individuals. We can have that special connection and we are deciding about certain issues, the medical community obviously could be a part of that, but again death is such an intimate event that nothing can strip away or change about me and how I will die, and we are still very flexible. We have a way to express our wishes about where we want to die and how we want to die. We are not mandated to die at this place or that place. We can undergo treatments or not. We can decide.

From this perspective, the MDC has relatively little sway over the individual. Each person has the individual agency to make their own decisions and have tools such as medical directives to ensure that they receive only the care they wish to receive. Though this may be the case for some members of the MDC, people are only able to choose from the options of which

they are aware. For example, advanced medical directives are only useful to someone who knows of their existence and understands how they are used.

Others, while agreeing that individuals make conscious decisions about death and dying for themselves, acknowledge that a variety of social forces and institutions influence individual decision making. The social institutions offered in their responses were politics/government, media, religion, and the private sector/insurance agencies. S-I stated, "Well, I think people would like to think they have control over their own death. Unfortunately, our government and insurance companies play a huge part in how they play out, but ultimately God is the only one in charge no matter what you do." Again, it is a combination of these institutions and their influence on the individual which define the MDC. As these institutions affect our lives uniquely, the experience of any individual may be very different that of another. For example, if a person attends church, than their understanding of death may be more heavily informed by the institution of religion than someone who does not attend church.

When asked who held authority over death in the United States, S-D, a volunteer coordinator, states, "Medicare." S-D tells of the experience of an elderly man who was denied coverage for his hospice care because the decline of his health did not meet Medicare Hospice standards. "We had to take a person off of hospice who was 102 years old because we couldn't show any decline. 102! When you hit 100 you should be able to be on hospice for the rest of your life!" In the United States today, a person must be certifiably dying in order for them to receive hospice services. This requires the hospice organization to document the decline in the person's health at a rate which satisfies the Medicare criteria. If a person is not wealthy enough to pay for end-of-life care from their own means, they may only receive hospice benefits if they die in a certain way. If they do not demonstrate decline in the specified way, they risk losing

coverage. Hospice services are also only available to those individuals who have ceased to seek extensive curative treatment. S-E, a hospice case manager, added this sentiment, "Look at something like a 30 year-old and they are doing every possible clinical study imaginable just to spend a year with their kid so they don't qualify [for hospice] but we could be working with that family but we can't. That frustrates me." In this way, the Medicare system drastically influences the death experiences of those within the MDC. If one's dying experience does not meet the definition of the influential health care institutions who define the death and dying process, the availability of end-of-life care within the MDC becomes limited.

As S-F, a palliative care doctor, states, "It's a law, just a silly, made-up thing." The hospice Medicare benefit can be seen as a form of social control which constricts the availability of care resources to the individual. The emerging palliative care field can be seen as an attempt to circumnavigate the authority structure while providing the same services earlier in the disease process.   While autonomy may be exercised by the individual, social forces surely affect what options are available to a person as well as how these options are perceived by that person and those around them. In this way, the influence of the MDC infiltrates the individual to the point of informing the definition of their own mortality.

Another social institution the respondents describe as having power over death in the MDC is the medical community. As the PCW is contained within this institution, their perspective on how death is handled by doctors and other medical professionals comes from their direct experience. S-B describes some of the difficulties she encounters from medical providers outside of hospice.

> Some providers feel that hospice is only applicable when the doctor can't do anything else. Others feel that if I mention hospice, then you might lose hope in me as a provider. Others feel that I can do it myself without hospice, but we find that the mentality of care

is different if for pain-management or for treatment…in America, we're into saving lives and living as long as possible, but what about personal choice and quality of life?

Again, the individual may only choose from the options that they are aware of. If a doctor does not mention hospice or downplays its utility to the individual, then that person may be never be aware of options that are available to them.

S-F highlights a further issue within the medical field. S-F described how S-F is able to speak to patients in a way altogether different than doctors within other specialties. This is due to S-F having the proper "time, role and skill," as S-F put it, to talk about death. S-F stated that many doctors are not exceptionally skilled in talking about death. Others have busy schedules and do not have the time to offer comprehensive death support. Still others are in the position of diagnosis. In this instance, the role of the doctor may inhibit their ability to candidly question the patient about their experience with their disease. The patient comes to them for information so the doctor in that role may focus on the disease, as opposed to the whole personhood of the patient person. As S-F has the time, role and skill to talk with patients and listen to their concerns, S-F is able to offer a type of care other doctors cannot. This discussion highlights both the shortcomings of the medical community in caring for the seriously ill as well as the attempts by some in the MDC to counter them.

A further criticism S-F raises regarding the medical community is a lack of home care support in the MDC. S-F describes how individuals only receive care when things are seriously wrong. "Our medical system does not help those who need light medical intervention or support in their homes." In this way, S-F describes care in the United States as "disease care, not medical care."

Though visibly important to several of the respondents, religion was never discussed in depth as a source of authority. This may be due to nature of religion in our society. S-B noted that S-B wondered if schools did not teach about death because it brought up issues of church and state. It may be that the religious connotations associated with death do keep teachers from entering into these sorts of discussions with students. Lack of death education in schools may result from a number of other variables as well. It does seem likely that as the PCW must be prepared to honor any religious belief in a patient, they are practiced in downplaying their own spirituality. Overall, clergy and God were mentioned as sources of authority over death by some, but only S-A, the chaplain, spoke extensively about spirituality and death. S-A notes that S-A's beliefs brought S-A comfort as S-A was confident S-A would be reunited with S-A's loved ones in the next phase of existence.

Another aspect of the MDC described by the respondents was the social forces that influence how we understand life and death. As individuals weigh decisions in their lives, they may consider what the social reaction will be to their choices. The same is true regarding death and dying. If a person decides to end aggressive treatment for a terminal illness, that decision will carry a certain reaction from those around the individual. The way life and death is understood within the MDC informs the nature of these reactions. If, as a society, we understand death to be inherently negative, then dying will be understood as bad. If dying is bad, then accepting death, even as someone who is very ill, may be deemed deviant by members of society. This deviance may then be explained as weakness or as the individual "giving up", as S-F phrases it, when in fact death waits for all humans and will come whether it has been accepted or not. S-B noted that as a society, we expect "instant gratification", stating that, "We're still hoping for a quick fix late into the dying process." If cultural expectations lead one to believe

that any problem can be solved, then the notion that death cannot be overcome may seem troubling. S-I summarized the situation in this way, "We can keep people alive for a very long time, at a great cost both financially and emotionally. The question that isn't asked is we can start everything [treatment] but when do you stop?" If friends and family are not prepared to say goodbye to a loved one and medical directives are not clearly indicated, then an individual may be kept alive for a substantial amount of time despite low quality of life.

Authority over death in the MDC is not static or fixed in any single location. The power structure is the culmination of a variety of institutions and social forces which influence individuals and inform how they understand life and death. For an individual to maximize their autonomy, they must be aware of all of the options available to them. If certain forces or institutions restrict the choices open to the individual, then their authority pushes back against the agency of the individual.

Assessing the Modern Death Context

The normative thoughts and behaviors described above do not capture the MDC in its entirety, but they do provide a slice of that context. In regards to how these norms shift and flow over time, I again offer microcosm of the way this can happen. The PCW respondents were asked about society's relationship with death. They described what we currently do well as a society, what we could do better, and what we should expect in the future. Their responses indicate the social trends they notice, their hopes for the people of the future as well as insight into the social mechanisms which affect the MDC.

I will begin with the respondent's perspectives on what needs improving in regards to how death is managed. In a sense, this critique is a description of those components of the MDC

which the PCWs believe are working poorly or should be changed. These criticisms revolve

around the normative understandings and behaviors within the MDC.

In terms of facing the topic of death, S-B stated, "People don't want to think about their

own mortality so they put off the decisions." Not facing death appears to be a normative aspect

of the MDC. Here, S-B describes the outcome of this practice by mentioning that when death is

not faced, death decisions are not made. This is a fundamental problem in the MDC, as many

people are forced to make difficult choices in their final days and may not be prepared to do so.

S-I agrees:

> We could demystify how scary death is and begin talking about end of life care and goals
> much earlier in the process instead of waiting until the 11th hour. Then you're coming in
> in crisis mode in the 11th hour. We do our best, I think we do great work but it sure
> would be a lot easier to get involved earlier.

Others note that families in the MDC are more disparate now than in previous times. S-D

states, "That's a negative in our society, we're so transient. You've got that and you only have a

couple of kids anymore [as opposed to previous time periods]. So here's mom and dad at home.

Jonny move to LA and Suzy moved to New York and there you are all alone." S-H agreed that

the notion of caring for one's elders is not as common in today's youth. S-H states:

> A big negative I see is the weakening family system which has a negative impact on
> death. Part of it is that families move away but it's also a generational thing. People in
> their twenties and thirties today can be very selfish. They often seem to view caring for
> their parents as an inconvenience.

These issues all revolve around the fact that death familiarity is not being provided by the

MDC. It may be that younger generations today are more self-focused but without familiarity

with death and dying, the sense of urgency regarding the care of their parents may not seem so

pressing. S-E agrees that families in the MDC do not support one another in the way S-E notes in other cultures.

> Certain cultures do rally around their family, we don't see that as much here in the Midwest, or in our hospice I should say, but I know some cultures have very specific ways about how they come together to support each other. They may have several generations living in one house and they just know how to care for one another. It's not like that here.

Here again, the respondents seem to be comparing the pre-modern tendencies of death familiarity to those of the modern death context. As their criticisms show, the modern approach is different than in times previous and at least for some, leaves holes in terms of family support.

The PCWs believe there are some aspects of the MDC which are serving us well. S-C states, "I think it's good that we have rituals like funerals to help people grieve and hospice helps a lot of people." S-H agrees there are aspects of how society manages death today which are advantageous. "We are slowly gaining awareness about end of life care and just how important it is." S-I stated that the hospice services are available and if an individual can be connected into that system, than they will be well cared-for. "When we [hospice care] get in and let people know what services are available, be it spiritual support, psycho-social support, medical support, it's there and if that can be pulled in…We do really well once we get them in [hospice]." The problem is that many individuals are not aware of hospice or believe it to be something unpleasant. Until this stigma is lifted, PCWs will continue to struggle to meet the full need in the community.

When asked about the future of palliative care in the US, the respondents noted that a shift in awareness is occurring within the MDC. S-A described the change in this way. "Slowly we start to talk about death and dying and we start to not push it away from us." S-I agreed about the rate at which attitudes are changing. "Ever, ever, ever so slowly [things are changing].

It's [death] still the D-word…" Death is therefore something which is still somewhat deviant to talk about. Though awareness may be moving slowly, S-F reports that the field of palliative medicine is growing "rapidly, in leaps and bounds." S-F went on to mention that "denial of death becomes an illusion at some point." From S-F's perspective, we as a society have denied death long enough and it is now time to face it head-on. "Our approach is countercultural. We are the cultural firemen, who run towards death while others run away from it." In making this statement, S-F is highlighting the deviance of facing death. S-F is also working to influence the future of the MDC. By striving to bring death back into the normative experience, the PCW hopes to empower the individual.

The modern death context, of which only a portion has been explored, provides the context of death and dying in society today. The various forces, institutions, normative and deviant beliefs and behaviors all culminate as the backdrop for the experience of the individual. It is this context which influences and informs its members. It has been shown that this context does not readily provide death experience. Beyond this, there are numerous institutions and social forces which influence individuals and affect their decision making process. By trying to educate those around them about palliative care, the PCW is attempting to influence the MDC in return. My analysis now turns to a closer examination of the process of acquiring death familiarity.

Death and Dying from the Standpoint of Familiarity

As many normative understandings and interactions within the MDC are based on the normative experiences of those within that context, those interactions and understandings are

often founded on unfamiliarity with death. Similarly, the understandings and interactions of the

respondents, who are familiar with death, are founded on the experiences of being active

members of a hospice or palliative care team. For the respondents death is witnessed, pondered,

talked about and normalized. In this section, I explore the standpoint of being familiar with

death. Several of the respondents note that as they have gained familiarity with death, their

understandings of death and dying have changed. This shift centers on an acceptance of death.

For some of the respondents, the standpoint of familiarity also brings a sense of responsibility or

duty to their work. As they occupy a rare standpoint with privileged understandings, they work

to spread this familiarity to others in society. Familiarity with death also helps the PCW create

and refine an understanding of what it means to have a "good death". Discussion of this concept

highlights how the PCWs categorize their understandings of a good death. This practice allows

them to ponder death personally without imposing their ideals onto the patients they work with.

Gaining Familiarity

As previously discussed, becoming familiar with death, especially earlier in one's life, is not

a normative experience in U.S. society today. Gaining familiarity requires experience with

death. Being near the seriously ill with some frequency encourages one to consider their

mortality. Thinking and talking about death is one of the most basic ways to become more

familiar with it.

For the PCW, death becomes less and less shocking. The workplace becomes a setting in

which the PCW experiences death repeatedly from a professional standpoint with the support of

a team. S-D was asked what it was like to spend so much time with people facing death. S-D

said, "Certainly we sit here now and say we aren't ready, but when the time comes, I think working through this position and working with people that are dying, it's not anything we really need to be afraid of." Though S-D lived with the normative unfamiliarity with death for some of S-D's life, working near death granted S-D the ability to view S-D's mortality with acceptance. S-A describes how S-A's acceptance of death acquired through S-A's work was tested by the death passage of S-A's mother:

> My mom died six years ago and I thought, you know, I had been with hospice for many years, my gosh, I know what's going on, what's happening and how it would affect me, but after she died, I was kind of emotionally changed. I experienced death on such an intimate level after losing my mom...but I think that when my mom died, that was the time when it literally changed my perspective, even from the spiritual perspective.

S-A's experience indicates that death familiarity has multiple layers and is a process more than a reachable state. One does not become familiar with death; one becomes more familiar with death than they were previously.

Like S-D, many of the respondents I spoke with began their employment with the normative unfamiliarity with death found in the MDC. Their familiarity with was typically acquired through their employment. This was not true of S-H. S-H was raised on a farm and experienced death early in S-H's life. S-H notes that along with the crops and animals which routinely died, S-H also interacted with nursing home patients who eventually passed away. These experiences left S-H with a perspective of death which is very different from the normative one held by many of S-H's peers. "I see death as a beautiful thing. I know that death is part of the lifecycle. Everything living will eventually die." As S-H was socialized to accept death from a young age, S-H never learned to fear the topic. That is how S-H was able to acquire S-H's familiarity before beginning work as a hospice social worker.

S-H's experiences more closely resemble that of the pre-modern experience of dying described by Lofland (1978) than the current MDC, though many people in today's context likely have experiences very similar to S-H's. Interaction with death allows one to acquire death familiarity. One of the reasons death familiarity was more common in the pre-modern context is that people were much more likely to die in infancy, childhood and adolescence than is common today. This meant that members of the pre-modern context were much more likely to experience death in their daily lives. It also meant that a family member of any age could die, often quickly and unexpectedly. Thus, even children of the pre-modern context were presumably familiar with death. As S-H constructed understandings of death acceptance in childhood, they seem to preclude the aversion to death found normatively in the MDC.

Seeing Death Differently:

Perspectives from the Standpoint of Familiarity

While the PCW gain familiarity with death, they come to view the topic differently than before. For these respondents, death cannot be denied. Through the course of their employment, they interact with death repeatedly. At some point, they begin to accept death and construct meaning around the topic. The primary shift in how the respondents understand death is a shift towards an acceptance of the process. Like S-H, many of the respondents come to view death as a natural occurrence. S-C states, "My view of death has changed. It's still hard for the people who are left behind but it's part of the life cycle and it can be a beautiful experience." This understanding normalizes the process and explains away some of the mystery of death. S-I states, "It's not that I approach it [death] lightheartedly, in general. I probably just approach it

with more acceptance and I don't question it as much." Accepting death as something beyond one's control frees the PCW from some of the anxiety found in the MDC.

Understanding death with acceptance is only one of the alterations the PCW make. S-F describes how being aware of the language we use regarding aging and dying should also be considered. An example of this is S-F's use of the word "developing" in place of "aging". Aging implies slowing and moving towards death while developing implies change and improvement. As the MDC is constructed of thoughts, words and behaviors, language is a crucial part of this social construct. S-F also warns of the danger of labeling any group of people "dying". In a sense, all humans are moving towards death. S-F argues that designating a status of "dying" to some and not others places false divisions between people and makes it easier to view certain populations, such as the elderly, as an other-group to be marginalized. In this sense, referring to groups of people as the "dying" is another way that society keeps death at a safe distance from its members. Shifting language to more appropriate terms counters the normative views of the MDC and allows the PCW to describe death while still affecting social change. As described by the tenants of symbolic interactionism (Mead 1934), meaning in society is created through shared symbols. Primarily, this refers to a shared language which is used in social interaction. By altering language, S-F is actively constructing new meanings with those S-F interacts with.

Near the end of the interviews, the respondents were asked how their relationship with death had changed since beginning their work. S-A responds, "Seeing people dying almost every day, it helps you better understand what life's all about. You realize what's important in this life, what's of value and you see love." S-J agreed by saying, "It's [working near death] given me a different perspective, not on death but on living. We need to appreciate everything

we've got and live in the moment because you never know what is going to come tomorrow."

These responses indicate that working near death encourages the individual to consider their own

mortality. While many in the MDC might find the topic of their own death a rather unpleasant

topic to consider, the PCW use this topic as inspiration to live life to the fullest. They gain a

sense of the value of life through their interaction with death.

Like nearly everything in modern society, death is a difficult process to understand from

a distance. The respondents view this process with more frequency and from a much closer

social distance than most in society. They do not have the luxury of avoiding the topic, they

must face it. Understandings such as death as a natural occurrence allow the PCW to understand

death very differently than most members of the MDC. The shifting of language and meaning

surrounding death is in itself an agent of gaining death familiarity. These changes allow the

PCW to calibrate their understandings to their higher levels of interaction with death. As the

respondents find that the standpoint of familiarity eases their anxiety over death, they try to help

others find similar understandings.

Spreading Awareness

In their assessment of the modern death context, the respondents voice several concerns

regarding society's relationship with death. Overall, they worry that by avoiding the topic of

death, members of society shortchange their chance to prepare for it. Thus, many of the

respondents stress the importance of spreading awareness of hospice and palliative care. As they

occupy the privileged standpoint of familiarity, it is their experiences and understandings which

can help others through the dying process. Primarily, the respondents describe spreading

awareness of death through their interaction with patients and their friends and family but they

also use forums such as lectures and community education programs. In this way, the PCW can

be seen as agents of social change. This is especially true as the understandings they spread

almost directly counter the normative understandings of proper death management.

The first social meaning the PCWs hope to alter is the stigma surrounding those who

work with death. If hospice is equated with death in the mind of a potential patient who fears

death, then they may choose any other option of care. S-J states:

> That whole myth of hospice as the last straw so we don't want hospice. I think we as knowledgeable individuals need to pass the information around that it's not only for at the end. Hospice is about living and doing it right and with dignity until the end, in comfort.

Not only would overcoming this stigma allow individuals to face their mortality earlier in

life, it would also make the work of the PCW much easier. S-I said "I don't know that I've ever

talked to a family who hasn't said I wish we would have signed up earlier. I wish we wouldn't

have waited so long [to register for hospice care]." S-I also notes that if a potential patient is

familiar with hospice care, S-I believes they register for the care earlier in the disease process.

"So if another family comes along and they know somebody who's been on [hospice], we

probably get them a little earlier because they've had those conversations, but it's different if you

have someone who is not familiar at all." This is an example of how death awareness spreads

throughout society. As familiarity increases, the stigma of hospice is lifted. In this way,

experience with death is being reintegrated into the MDC.

The ultimate goal of the PCW is to facilitate meaningful and positive death experiences

for those in society. S-I says, "I think our job is to empower them [people in society], to teach

them and empower them and encourage them that they can do it! So many times they say I can't

do it and we say you are doing it! You've done it!" By teaching and empowering members of

the MDC, the respondents try to bring the ability to manage death back into the hands of the individual. Their familiarity has taught them that death does not have to be feared. The awareness they spread to the community should be viewed as an attempt to alleviate societal fear of death. The respondents state that death can be beautiful. The discussion of a good death explores how death can be viewed as a positive experience.

A Good Death

Death familiarity is gained through interaction with death. As the experience with death is acquired, the PCW see death happen in a variety of ways. This allows them to gain a sense of what constitutes a positive dying experience and how this experience can be achieved. In describing the characteristics of a good death, the PCW also remembers that a good death is defined differently by different people. In order to honor the various wishes and beliefs of their patients, the PCW must keep their personal views on death aside. Through this division of understanding, the PCWs gather a definition of a good death, which may serve as in ideal version in their personal life, while still being prepared to provide whatever services a patient may want or need.

Working near death provides the opportunity to consider one's own eventual passing. After watching death occur in a variety of ways, the PCW may decide that certain approaches to dying seem more appealing than others. Their familiarity affords them a diversity of dying experiences which, in turn, provides them with a wider range of options to choose from than others with a more normative conception of the MDC. This is not to say that the PCW is able to tell someone else the proper way that they should approach death. It simply means that when considering how they themselves would approach death, the PCW has a broader spectrum of

experience from which to craft their own ideal death experience. S-C states that S-C thought a good death consisted of, "A full life, peaceful death, pain-free, having the chance to say goodbye to loved ones and having the family present." S-F described what patients want as they face death. "When the times come, they hope that they can be comfortable and they hope they can die gently and then they hope their families do well. They want clear decision-making and a sense of completion, affirmation as a whole person". S-I notes that having one's business in order seemed to make the dying experience run smoother.

> It [finishing earthly business] sure seems to make things easier, especially with younger people. When I say younger people, I mean those who are probably leaving families behind, children that they're in charge of taking care of. I'm not talking about the elderly who are finished raising their children.

In her meta-analysis of a variety of scholarly articles relating to the concept of a "good death" Kehl (2006) concludes that a good death is "highly individual, changeable over time, and based on perspective and experience." This is similar to the understanding the respondents describe. Beyond specific aspects of a good death, the participants describe a loose-fitting framework that is fitted to each client's unique situation. S-E states, "a good death is exactly how a patient and family envision it, whether that's in their home or somewhere else, being comfortable, not being overwhelmed, the patient being symptom and pain free, to the end..." This understanding of a good death allows for the beliefs of the individual to be honored at the end of their life.

Death familiarity is difficult to obtain in the MDC. The perspectives of the PCW are rare and in many ways directly conflict with the normative denial of death found in the MDC. The PCWs face death directly and strive to facilitate a process which allows the patient to work towards a good death as they, the patient, define one. Facing death allow the PCW to gain

familiarity with the process. Eventually, death is accepted as natural. The respondents describe how this acceptance, in a variety of ways, changes how they feel about death. Their anxiety over death has lessened and they are now able to talk about the subject openly and even casually. While many in society avoid death, familiarity allows the PCW to create meaning around death with reframes the process as having great importance. Often, the respondents felt the responsibility to share this perspective with others, as they themselves found it useful.

Though the standpoint of familiarity seems to aid the ability of one to accept death, this does not imply that a person familiar with death cannot be emotionally affected by the loss of someone they care for. Death is final and for the PCW, saying final goodbyes again and again is not easy. In order to remain working near death over an extended period of time, the respondents describe the necessity of actively managing their emotions through the course of their employment. These efforts allow the PCW to maintain a professional dynamic with the patients that is empathetic yet emotionally sustainable.

DOING DEATH: EMOTION WORK
OF THE PALLIATIVE CARE WORKER

As is true of many jobs, working near death requires the worker to manage their emotions through the course of their employment. Providing palliative care, consisting of supporting seriously ill patients and their social network in a variety of ways, implies an emotional aspect to the work. The respondents describe a number of emotional demands they encounter through the course of their employment. Thus, palliative care meets Hochschild's (1983) definition of emotional labor. The following describes the emotional demands of providing palliative care as well as the ways the respondents meet these demands. These include an understanding of an

ideal emotional state for providing palliative care, the maintaining of boundaries with the clients they interact with and an understanding of death which makes their work emotionally rewarding.

In the interviews, the respondents were asked to describe the ideal emotional state for performing their duties as palliative care workers. Largely, this is said to depend on the state of the patients and friends and family they interact with. S-A states, "I try to meet them where they are. I try to connect with them by letting them know they are not alone." S-C describes the difficulty of working with people who are upset by the situation they are facing. "It depends on the person. If they're closed or angry, it's very hard to break down those barriers." Other responses regarding the ideal state for providing palliative care include being strong, calm, non-judgmental, supportive, accepting, positive, flexible, stable, controlled and empathetic. S-H states, "Being empathetic but not sympathetic. I know what it's like [to experience the loss of death] but I don't have that exact relationship so I don't pretend that I do. I try to be a neutral person to talk to." These characteristics allow the PCW to maintain a dynamic which offers care and support but does not sacrifice their own emotional well-being.

Beyond understanding how to interact with the seriously ill, the PCWs are able to protect themselves emotionally through their understandings of death and dying. Without exception, the individuals I spoke with expressed passion for their work. S-A says:

> I do [find the work rewarding]. Just knowing that I can bring people some comfort or some hope, you see how some people's lives can change after visiting with them for a while, from initially being scare and being anxious to at some point looking forward to that new experience. Also to bring comfort to the families, walking the journey with them, being with them in pain, it is rewarding.

By understanding death in a way that makes their work emotionally rewarding, the PCWs counter the emotional strains they encounter. When asked what it is like to work with the dying, S-E responds, "It's very rewarding. Many people think it must be sad and how can I do this

work. It's rewarding to be able to work with a family from just coming to accept a diagnosis to seeing them through what I would call a good death experience." Though at times S-E surely experiences sadness through the course of the work, S-E views S-E's employment as a positive experience.

Another way the PCW is able to protect themselves emotionally is through actively managing their relationships with their clients. S-H describes the ideal dynamic for interacting with patients and families in this way:

> Part of the balance comes from knowing these people as patients. We don't know them personally and we're just getting to know them at the end. So we hear the stories but we don't experience that with them and so again, honoring the fact that you got to hear the story, but it is very different in my personal life. I had a relationship with them, we were able to share stories together and it's almost like a part of me is gone with them. Working with death all the time, helping people celebrate themselves, I've definitely gotten closer with certain patients but it's still very different and I keep my life private so it's not really a full relationship. The relationship is only flowing one away, I don't reciprocate about myself.

This sentiment depicts how the PCW is able to distinguish between experiencing death personally and professionally, which protects them emotionally. S-H believes that to share one's life with another creates a bond. Restraining from sharing information about one's self allows S-H to guard S-H from experiencing death on more personal levels. This is also important in that it protects the PCW from becoming overly desensitized towards death. Death in one's personal life is simply experienced more personally, as that individual shares a portion of the PCW's life.

An emotional risk inherent in providing intimate care is either the staff or patient/family member becoming overly attached to one another. To account for this, the PCWs work to maintain a caring yet professional relationship. S-I states, "Oh, well the risk is getting overly involved, and you know what? It happens to every one of us. So constantly doing that boundary check." I refer to this effort as boundary maintenance. This should not be confused with

existing sociological concept of boundary maintenance described by Marshall (1998) which describes how societies work to create distinction or boundaries between themselves and other societies. S-I statement indicates that this risk and the practice of boundary maintenance are both very common in the work S-I performs. S-D agrees, "The demands are trying to keep it all together and not let the emotions carry you away. Not to get too caught up and that's very hard for the volunteers." PCWs understand that becoming overly involved makes the relationship personal, which ultimately detracts from the patient's experience. S-I further explains:

> It's there [the patient's] experience and if I rob them of that, then I'm doing them a disservice. I liken it to this, if you took a snapshot at the time of death, I should not, or the hospice nurse or the caregiver should not be in the picture. It should be the person who's going through it and their loved ones. We're there to support on the outside. We should not be in that picture.

While the PCW may practice boundary maintenance, they depend on one another as members of a team to be vigilant and vocalize any concerns they might have about a coworker and their relationships with a client. S-I says, "We call each other on it [becoming overly involved]. We work with a great team and sometimes you don't recognize it in yourself, but others can see it and say you know what? Time to pull back." S-J describes the process once this overly personal dynamic is noticed. "Once we recognize it [a coworker becoming overly involved] we try to take that nurse off of that case, for a short period if need be or confront them and say hey, you're getting too involved. What can we do to help you through this?" Team members often view actions such as taking calls or visiting patients while off duty signs of a relationship becoming overly personal. S-I states, "If I can't tell my coworkers something or think I shouldn't tell them exactly what's happening [with a client], then I've crossed a boundary line." S-J agrees:

Sometimes we don't catch it but we have staff that will do visits [to clients] on their days off. They take calls when they're not on call or if one of our patients dies and they want to be notified. You can also tell burnout by that exhausted look in their eyes, tears, always feel they have to know what's going on with a particular patient.

An example of how a PCW could become too involved would be if the patient in some way reminds the PCW of themselves. This may be due to a similar temperament or being the same age or having children the same age. S-B stated, "You relate to the patient if they are the same age as you or have a similar family. So when you relate on that level, some of you goes with the patient." It is this sort of sacrifice which can lead to what S-B terms, "compassion fatigue". S-E describes an instance when she became aware that she was personalizing a relationship with a client. S-E explains:

I had one patient who I had to sign over to someone else. That was just sort of a connective thing. There's always someone who's going to affect you differently. I think it depends on how much you interact with them and relate to them personality wise and just experience wise. Maybe it was just because she had breast cancer which what my mother-in-law died of.

When asked how he was able to maintain this ideal state if he did not truly fee that way at the time, S-A states:

Sometimes when I think about it, it's almost like I feel guilty that it becomes a routine every day and you think gosh, where's my heart? So sometimes I have to tell myself to slow down, find myself in the situation or where's my heart in all of this because when you deal with it all the time, it's almost like it becomes routine and you lose your compassion or your empathy if you're not connected and obviously we need boundaries in this work but sometimes, you have to work to meet that depth of emotion.

This sentiment agrees with the notion of what Hochschild labels "deep acting" (1983). By working to meet the required depth of emotion, the emotional labor of the PCW is clearly displayed. These individuals manage themselves internally to offer the emotional state that providing end-of-life-care requires. As S-A describes, this emotion management is not always

easy to perform. This understanding is shared by S-C. "Yeah I find I get really tired sometimes. Listening takes a lot of effort and responding back in a way which makes the patient and family feel validated." Due to its finality, death can be extremely emotional. As the PCWs work regularly in this setting, they must actively manage their emotions to protect themselves while meeting the demands of their work.

While the respondents describe their work as being emotionally demanding, they have number of ways in which these demands are met and overcome. In effect, they seem to customize their emotion approach to, as S-A says, "meet them where they are". By actively managing the relationship between themselves and their patients, the PCWs protect themselves from becoming overly attached. They also monitor one another as members of team. Accepting death allows the respondents to view their work as important and rewarding. In these ways, the emotional demands and risks of providing palliative care are countered.

V.

Conclusion/ Recommendations

Review of Findings

As has been discussed, the normative understandings of death described by the respondents largely agree with previous scholarly writing on the topic of death in modern society. In the opinions of the respondents, most people have little experience with death, even in adulthood. While this may be true of many, the respondents I interviewed all describe a relationship with death which is different than is normative in this context. After working near death for a period of time, they have learned to accept mortality as part of the human condition. Viewing death with acceptance allows the respondents to interact with death intimately, which in turn further deepens their familiarity.

The palliative care workers also use a variety of sociologically pertinent tools to perform their work. Accepting death serves to lessen the emotional strain of working near death. Beyond this acceptance, the respondents describe a constructed ideal emotional state for providing palliative care which allows them to assess how they can best support their clients. Performing boundary maintenance assists the PCW in protecting themselves from becoming over involved, and thus emotionally vulnerable. The constructed understanding of a "good death" aids the respondents in providing a flexible support system which can be adapted to a variety of settings and situations. Through the active categorization of meaning, the respondents redefine death and

understand it differently in different situations, such as at work versus in their personal life. This allows them to experience death differently in different social situations.

Through emotion management and a nuanced understanding of death, the respondents I spoke with transform the normatively morbid notion of death into one of reverence and celebration. These individuals have learned that death can be performed in a variety of ways. They strive to support the individuals they encounter however they can while encouraging them to face the situation directly. It should be noted that this approach to providing medical intervention is drastically different than most in our society today. By focusing on the patient as a whole person, one who requires multiple forms of support, the respondents transform the normative medical experience of what S-F refers to as "disease care" into a comprehensive approach which focuses on the individual and their wishes. In all of these ways, the palliative care workers are agents of social change. Though gaining familiarity with death is not necessarily easy, the respondents have faced death and now work to bring their expertise and understanding to the rest of society. They understand that much of the anxiety and fear of death is unnecessary. In certain cases, they note that becoming familiar with death has reinvigorated their interest in their time between the present and when they eventually die. This is a perspective which can only be understood from a standpoint of familiarity with death.

Research Limitations

There are several limitations of this research. While the responses of the interview participants were similar in many ways, it should be noted that eight of these individuals worked closely with one another on a single hospice team, while the other two respondents worked together in the same town. This naturally leads to some homogeny in the responses.

Furthermore, the respondents are practiced in describing and even defending their methods of care. This may lead the respondents to describe their work in a way that highlights the positive aspects and downplays the negative aspects. Furthermore this research is based on the understandings of a relatively small group of individuals within a single geographic location, a town of about 50,000 in the Midwestern United States. While the understandings of these respondents were found to be largely homogenous, they might be very different from palliative care workers in other parts of the county.

While this is true, the respondents come from a variety of backgrounds including being born in other states and other countries. While they all currently reside in a specific geographic area, their social experiences have been drawn from a variety of locations beyond the Midwest. They also voiced a variety of concerns such a frustration with Medicare hospice benefit. This leads me to believe that the respondents were largely speaking candidly. While these findings may not be generalized to the entire United States population, they do suggest trends in the specific geographic region in which they were gathered. Specifically, the experiences of the PCWs in this research are likely similar to those of PCWs in towns of the same size across the Midwest.

Further Research

As this specific research comes to a close, I would like to note several areas regarding death in modern society which deserve further sociological pursuit. The first of these areas is to focus on death awareness as a social movement. It would be interesting to explore the perspective of others in society who work to bring awareness of death and dying into the modern death context. This research could offer a sense of what the future death context might look like.

Another way to explore the future death context would be to examine deviant dying ceremonies, customs and beliefs in the U.S. today. This research could offer insight into the standpoint of societal members who are not bound by normative understandings. Performing this research would also help to define the nature of the current death context.

It would also be interesting to speak with people in society who have gained death familiarity in the younger years and are now facing their own death. This research would provide an opportunity see what familiarity offers the individual in their time of dying. As the individual understands death differently than most of society, how would this affect their experience?

Another area of society which deserves research would be to compare the familiarity gained by the PCW to those who have gained death familiarity through other methods. This would further outline the process of gaining familiarity and would describe the resultant death perspective gained through different types of death experiences.

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APPENDICE A:

Interview Schedule

The questions I will ask the hospice employees will pertain to a variety of topics. Primarily, I will be interested in learning what is like to become a death specialist, their perspectives on the nature of dying in our current society and the ways they manage their emotions around death in the workplace as well as in their personal lives. These questions will be aimed at eliciting narrative responses from the subjects. As such, follow-up questions will be asked to clarify and further explore the initial responses.

A. Background/ Becoming a Death Specialist.

-How long have you worked in the field?

-What lead you to be interested in end-of-life care?

-What is it like to work with the dying?

-What is the goal of the hospice approach and how is it unique?

-What, if any, previous experiences with death did you have before this job? Can you tell me about them?

-Were you comfortable with death when you began this work? What were your thoughts on death before you started working here? Are you comfortable with death now? Tell me about your current perspective on death.

-Have your views on death changed since beginning this work? If yes, how so?

-Do you experience death differently since beginning this work?

B. Death in Today's Society

-What do you think it is like to die in the U.S. today?

-What is the typical or average death experience like? Can you take me through an example?

-Who, in our society, is in charge of the dying? Who has power/ authority?

-Where does the hospice approach to end-of-life care fit into our society?

-What are the positive/negative aspects of our current ways of dying?

-What is changing in regards to death and dying in our society?

-Do you think our social perspectives on death should be altered? Why? What would you like to see changed or incorporated into our views on death?

C. Emotion Work

-How does it feel to work with the dying? What is it like to be around death often?

-What are the emotional demands you encounter in your job?

-How do you meet these demands?

-Is your work emotionally rewarding?

-What is the ideal emotional state for providing end-of-life care and how does this affect the dying individuals you work with?

-How do you support someone who is facing the end of their life?

-How do you prepare yourself emotionally for your day at work?

-Has the way death affects you emotionally changed over the course of your employment?

-Has hospice work affected how you feel about death?

D. Closing

- Is there anything else you think I should know before we end?

-Is there anything that came up for you while we were speaking that you would like to talk about?

-thanks and closing