Recognizing, Relating, and Responding:

Hospice Workers and the Communication of Compassion

by

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ABSTRACT

In a mere thirty years, hospice has grown from a purely ideological philosophy of care for terminally ill individuals and their families, to a large and well organized healthcare entity. And government statistics project that healthcare will generate more new jobs than any other industry in America until at least 2018. While most of the extant literature that has been published on healthcare workers has focused on negative organizational processes, such as stress and burnout, there has been a recent shift in scholarly ideology in which researchers have been challenged to consider the positive aspects of organizational life as well. Compassion, theorized as a three-part interrelated process, is one area that is garnering interest within organizational studies.

Utilizing grounded theory, this study engaged literature from organizational studies on emotional labor, stress, and burnout, as well as literature on positive organizational communication. What emerged from the data is a richly detailed picture of the emotional highs and lows that hospice workers experience in their jobs.

Research was conducted at two large hospices in the desert southwest, utilized qualitative methods of participant observation (161 hours), and informal and semi-structured interviews (29 interviews) as a means to understand hospice workers—nurses (32), nursing assistants (23), social workers (14), and spiritual care providers (4)—experiences of emotion. Through data analysis, compassion emerged as a salient concept in worker's daily experiences. Yet, my data suggested a reconceptualization of he way in which compassion has been theorized in the past—as *noticing*, *feeling*, and *responding*. Based on my findings, I argue that the three subprocesses could more accurately be described *recognizing*, *relating*, and *responding*.

Additionally, findings reveal that compassionate communication does not necessitate all three sub-processes to be present, unfold, or interact according to current linear conceptions. I offer a model and visual representation of compassion that I believe better conveys compassion as a holistic interrelated process in organizational contexts. This model suggests that *responding* is the heart of compassion, while *recognizing* and *relating* fill and complete the compassionate heart. The study concludes by identifying theoretical and practical implications for both hospice organizations and organizational scholars.

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My dear friend and mentor *Dr. Linda Park-Fuller.* Linda was not only my original dissertation chair, but also one of my favorite professors. I love her for the strength of her convictions, her bountiful wisdom, and consistent advice and guidance. She is yet another person I am honored to call my friend.

My family: My brother and sister-in-law, *Steve and Kim Copley,* who are alive in every part of this dissertation. It was our mother's death in 1998 that served not only as the impetus for this dissertation, but also the event that enabled

Steve and I to create and nurture the bond we have today. His beautiful wife Kim has been a great support and is like a sister to me. My son *Joe Way*—When my mother was in the ICU unit recovering from surgery to remove a brain tumor, Joe wrote her a letter, which I read to her as she lay recuperating. Although mom was in a drug-induced haze, I was moved to tears by the beauty of the words he wrote to her. I thought of that letter often through the writing of this dissertation. It constantly serves to remind me of what a sensitive, caring and outstanding man you are. My granddaughter *Katusha Way* has been a consistently motivating influence on my completing this dissertation. I want her to be proud of her grandma and know that no matter where life takes her, she can be anybody and do anything she sets her sights upon. *Bob Dougherty*—No one has been more supportive of my academic endeavors than Bob. He encouraged me, believed in me, and supported me through all the highs and lows of not only my academic life, but also my personal life for the last twenty years. I hope that he will always be someone I can call a friend.

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FORWARD

This dissertation has evolved over many years of graduate study, and has undergone numerous iterations. And I would not hesitate to say that *this* dissertation would not exist if it had not been for my personal experience with hospice when my mother was dying. To say this one event was life changing is, of course, overly simplistic. My relationship with my mother was complicated and contentious, and I look back on her life, our relationship, and her death with much sadness and many regrets. Nonetheless, one immense joy was borne out of the experience of my mother's death—the relationship I have since gained with my brother. I don't think we would have the relationship we do if it were not for having lived and experienced the deaths of our parents, who died within sixteen months of each other. When I began my first research project with hospice in 2004, it did not take long for me to realize that old and often unresolved feelings were resurfacing, and I began journaling about my hospice experience. What follows now is the result of some of that writing, or what Van Maanen (1988) refers to as a confessional tale. As Van Maanen (1988) states, confessional tales "are intended to show how particular works came into being, and this demands personalized authority" (p. 74). I wanted to include it in this dissertation as a way to pay tribute to my mother, her hospice caretakers, my brother and me. It is my voice, my story, and my narrative of life, death, dying, hospice, and compassion—present and absent.[1]

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The 1990’s were what I refer to as “the decade of death.” Nearly every relative I had over the age of 65 died during that time. A section of my closet was devoted to funeral-wear. One outfit wouldn’t do because many of the same people were attending the same funerals, and if there was one lesson I learned from my mother, it was that a gal has always got to be well dressed, even at a funeral. As cliché as it may sound, what the decade of death did for me was lead me to accept the realization that after birth, there is only one thing every human can be assured of: death. And like every life, every death is unique.

My grandmother was the first of my family to die during this time period. She died in a convalescent home at the age of 95. She had suffered from Alzheimer’s for more than 10 years, and although her mind had slipped away, her body seemingly refused to quit. When I visited her in the hospital ward of her convalescent home two days prior to her death from pneumonia, she looked directly into my eyes with the most clarity I had seen in years. I do think at that very moment she remembered me, and to this day it is the image that comes to my mind when I think of my grandmother.

Next to die was one of my dearest and most beloved aunts who died in a hospital in immense pain from leukemia. She had lived a long, full and happy life, and thankfully had not suffered long from the disease. In her final days she told her husband, my uncle, that she wanted to die because she could not bear the pain any longer. My uncle was nearly deaf and had come to depend on her for almost everything. They were best friends and life-long partners, having been married for over 40 years, living in the same house they built together after they married.

After she died, he could not bear the loss. After discreetly giving away their belongings to friends and relatives over a year's time, he went to his workshop and put a rifle to his head. Inside the house, he had taped notes and messages to various items; the phone number for each utility company was on the desk and the number to the newspaper was taped to the inside of the front door, along with instructions for terminating the services. The remaining household items were tagged with the names of the people he wanted to have them. It seemed as if he did not want his death to be a burden, taking care of as many details beforehand as he could. Or perhaps, he just wanted to write the final chapter of their lives and not leave it up to fate, relatives, or attorneys.

Yet, it is the stark disparity between my parent's individual deaths that is most striking. My father, at the age of 70, suffered a heart attack so severe that the doctors said his death was instantaneous—no prolonged pain or suffering. They said he was literally "dead before he hit the ground." He had just finished lunch at the local coffee shop with his cronies, just as he had done every day for the previous 4 years. He got up from the table, and fell to the floor.

My mother on the other hand, lingered in her death. She had had lung cancer, the result of 50 years of smoking cigarettes, and the cancer subsequently metastasized in her brain. Over a two-year period she underwent multiple rounds of chemotherapy, radiation and surgery. Although there were no final "good-byes" that could be said to my father, no one—friends, family, or my father—had to contend with the discomforts of a lingering death. Conversely, while farewells could have (and should have) been possible with my mother, they were complicated (if not made impossible) by prolonged attempts at medical interventions, the harsh and rapid loss of her bodily functions as her brain succumbed to the ravages of the cancer, as well as the volumes of psychological and emotional baggage that had plagued our family dynamics for years. My father did not have the opportunity to write his final chapter, and my mother avoided picking up the pencil.

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I don't remember exactly when I learned of my mother's cancer. Unlike my father who had almost never had a completely healthy day in his life, my mother had been quite healthy her entire life. I'd always hoped that my own genetic make-up was the result of deeper swims in gene pool of my mother's family than my fathers'. After all, my mother's mother had lived to see 95, and my mother had been a smoker for nearly 50 years with no apparent health repercussions...up until now.

I vaguely remember my mother calling to say that she had had a chest x-ray and the doctor spotted something on the image and wanted her to get a biopsy. I thought that it was probably just a poor quality x-ray and that the biopsy would prove to be negative—how else could you explain someone who had smoked for so long and still appeared to be completely healthy. Surely she wasn't actually sick. She asked if I would go with her to the doctor for the biopsy. An unenthusiastic "sure" was my only response, precisely because I thought it would prove to be unnecessary. And given that the drive to her house entailed, even in the best of circumstances, a grueling two hour commute through LA traffic, I was feeling a little put out.

On the way to the doctor's office she told me how she had discovered the enlarged lymph nodes several months earlier. She knew that something was wrong, but didn't do anything about it at the time because she was in the midst of organizing and planning her 50th high school reunion. I remembered how important that event was to her, and all the preparation and planning she had been putting into that one weekend in March of 1996. Besides official duties associated with being on the reunion planning committee, she was engaged in seemingly endless rounds of cosmetic treatments and shopping trips so that she would feel quite sure that she was the best looking 68-year-old woman in attendance. She said she was afraid that if she went to the doctor to have the suspicious growths investigated before the reunion, it would have ruined the weekend. I have never had a high school reunion, nor would I ever—at seventeen and pregnant, I dropped out of high school. So while I first thought her 'excuse' for not seeking medical attention months sooner was unconscionable, ultimately, I just considered it something I would never be able to understand—maybe high school reunions were that important.

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During the week, we had full time care for mom—two home health aids each working one twelve-hour shift, five days a week. My brother and I would alternate weekends. On my weekend, I would pack a few things in a small suitcase, and make the drive to Orange County. If I left before noon, I could make it in a little less than 2 hours. Any later, and the trip could turn in to a great many more hours. As much as I hated the LA traffic, I would sometimes find myself undertaking busy work at home on those Friday mornings—work that clearly didn't need doing, and could easily push me past the crucial twelve o'clock cut off. Even though the traffic would be brutal, I knew that what awaited me at mom's house would be far worse. Thus, if the trip took three hours instead of two, so be it. At least in the privacy of my car, I could turn the radio up as loud as I wanted and alternate between singing and crying.

Over time, the suitcase I packed turned in to an overnight bag, then a small, flimsy, used plastic grocery bag. By the end of those months and my mother's life, I am quite sure I never showered while I was at her house. Weekends were spent endlessly and exhaustingly doing 'things.' For the few hours that mom actually slept, I didn't want to waste them bathing—I just wanted to sleep.

You see, my mother was a fidgety person. She was always moving. Always. I remember a trip we made together in 1985 to Stockton California to attend the wedding of a relative. We made the incredibly boring six-hour drive up and down Interstate 5 in her little Toyota Corolla. I drove up, so it wasn't until she was driving back that I realized just how fidgety she actually was. Even though she was at the wheel, she was very busy—lighting a cigarette, adjusting the air conditioning up, then down, then up, up, up, then down, then putting out the cigarette, the radio, the rearview mirror, something in the glove box, then another cigarette…I was exhausted and I hadn’t moved from my seat for six punishing hours.

Although she was now ill and couldn’t walk, she was no less fidgety. Only now, her hands and legs were not her own. Her hands and legs were mine. She was a puppeteer pulling the strings of her subjects from her living room sofa—a glass of water please, don’t forget to refill the water pitcher, are you sure you filled it up, you’d better check, turn the TV up, down, the heat, how about some fresh air, open the window, no it is too cold, is that dust on the counter, I’m hungry, I’m hungry, I’m hungry. The combination of drugs that she was taking gave her a voracious appetite. So hungry, she would wake up in the middle of the night for a bowl of cereal to sustain her until morning.

She spent the last month of her life living on her living room sofa, right up until a hospital bed was brought in 2 days before she died. She refused to sleep in her bed. I once tried to convince her that she would be much more comfortable there. I even got her to consent to give it a try. I pulled her up off the sofa, put my arms around her waist for support, and we slowly edged our way down the hall to her bedroom. She lived in a small mobile home and her bedroom was at the very back of the coach. It was a tiny room and only had one tiny window, but it was nonetheless her room, her meticulously decorated and maintained room—I thought she might find some comfort there. No sooner did I get her to the edge of the bed, however, that she stated to hyperventilate. She was having a panic attack, and I was terrified. The trip down the narrow hallway to her room took no less than 10 minutes because of her nearly nonfunctioning and spastic legs. How the hell was I going to get her back to the sofa…and quickly? Somewhere deep inside me the adrenaline began to pump and I found the strength to lift her off the bed and half carry, half drag her back to the safety of her green sofa.

I don't know what happened in that room that day. Maybe the tiny space was just too confining, too tomb-like. But I never mentioned that room to her again. So she continued to sleep on the sofa, and when she would finally fall asleep, I would duck into the guestroom, the room that lies just on the other side of the living room. I would lie down on the small mattress and listen through the paper-thin walls to each and every breath she took, waiting for the inevitable call for middle of the night cereal.

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On the last night of my mother's life, her doctor sent over a bottle of morphine. She was fitful and her breathing laborious. The directions on the bottle said to administer 10 milligrams by mouth every four hours. But as the night wore on, her pleas for more came every half hour. How could I deny this dying woman the drug that would alleviate her pain? But to do so, would mean greatly exceeding the doctor's orders. I wondered, how much morphine I could administer before it was me that killed my mother, and not the cancer. My hand shook and tears welled in my eyes each time I brought the dropper filled with the potent drug to her mouth. Yet each time the drug went down her throat and she gagged from its bitterness, it seemed to render no effect.

When her nurse arrived the next day, I asked her if mom was dying. Of course I knew she was "dying," but was I actually watching it happen right before my eyes? She said, yes. What she was exhibiting was "terminal anxiety," a state of fitfulness that comes right before death. I was alternatively relieved and angry—relieved that she would soon be at rest, and angry that no one had told me that this is what it would look like. I thought that that was what they were supposed to do, prepare both my mother and myself for the actual physical realities of death and dying.

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February 5, 1998. 7:58am, 16222 Monterey Lane, Space 58, Huntington Beach, CA

I sit on the edge of Mom's bed, staring at the clock. I hold the phone in both hands for fear if I use just one, I will drop it. My whole body shakes in near convulsions, the result of weeks of watching someone die. I stare at the clock and watch the second hand as it makes its way around the dial, in seeming slow motion. Every…second…feels…like…an…hour. 7:59. One more minute to go until the hospice office would open. In the hospital bed that now sits in the middle of the living room, I hear Mom moaning, thrashing. Tick…tick…tick. She calls my name, "Debbie…" The second hand makes its final assent towards the top of the dial. I begin punching the numbers now engrained in my memory. There is ringing on the other end, then, I hear it, "Beach Cities Hospice." Tears begin to flow uncontrollably. I cannot speak, only cry. But I cry as if in a whisper. Loud enough for the hospice nurse on the other end of the phone to know I am there, but softly enough not to be heard by my mother in the next room.

My mother died that day in February 1998. She had been under hospice care for only two weeks. She spent most of the final months of her 69 years trying to avoid the existence of the cancer ravaging her body and mind. When I called the hospice agency in the middle of that last, emotionally draining night, I got the answering service and was told I wouldn't be able to talk to my mother's nurse until the office opened at 8am. Not wanting to be a "bother," it never occurred to me to insist. So I waited. However, within two hours of my 8am phone call, her nurse and social worker arrived at her home. As I sat in a near coma-like state of emotional exhaustion, and my mother struggled for breath, they administered drugs, placed phone calls, found a nursing home that would accept her, and arranged for an ambulance to transport her. They also casually talked amongst themselves about their families. They made quips, smiled and laughed. They talked to the administrators of the nursing homes and ambulance companies as if they were old friends wanting to catch up on each other's lives. In the first few years after that day, I thought frequently about that nurse and social worker, convinced that under their cool and calm demeanor was a mangle of misplaced, mismanaged, and maladjusted emotions. Otherwise, how could it have been possible that our pain and suffering didn't move them to immobility, as it had me? How, I had often wondered, could they do that job, day after day, year after year?

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An ambulance took mom to the nursing home in Santa Ana that agreed to take her. After they pulled out of the driveway, and her nurse and social worker left, I locked up her trailer and drove myself to the home. By the time I arrived, they had her in a room and were trying to stabilize her constant thrashing—she was fighting death every step of the way. As a nurse tried to insert a catheter, I tried to calm her, telling her to relax, to quit fighting, "Please mom, let go. Everything will be O.K."

The hospice chaplain arrived at the same time the nursing homes' administrator came in and asked me if I would like something to eat. Although I wasn't hungry, when I tried to recall the last food I had eaten, I couldn't remember—maybe it was yesterday, maybe the day before that. Without yet responding, she took my arm and pulled me out of mother's room and into her office two doors away. As I waited for food to arrive from the cafeteria, she poured me a cup of coffee from the thermos on her desk. As I sipped the coffee, I heard singing. It was the voice of the hospice chaplain standing at my mother's bedside, singing Amazing Grace.

I knew it would all be over very soon.

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As I reflect back to the day when my mother died, and the four years between that day and my first study of hospice nurses, I would never have believed that I would study hospice workers, much less write a dissertation about them. I recall a day when I was collecting data for this project and spent the day in the field with one of the social workers, Sarah. She covered a large territory, which included visiting a rather small rural community. In that town, one of her duties was to lead a grief support group held a local funeral home. The day that we visited, no one came to the support group, which apparently wasn't terribly unusual. The funeral director was tending to a recently deceased community member, preparing his body of the funeral. By this point in my studies with the two hospices I was working, I had been with a number of people when they died, and had seen many more deceased bodies. But I'd never seen one at a funeral home being prepared for family viewing. So I asked the director if I could watch. Without hesitation he said, "of course," and off to the back room we went.

As I stood intently looking at and watching the funeral director and the dead man, I remember thinking back to the day my mother died, my bewilderment at the cool and collected calmness of her nurse and social worker, absolutely sure there was something terribly wrong with them. Ironically, there I was, cool, calm and collected, absolutely sure there was nothing terribly wrong with me.

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[1] For the purpose of this narrative, I adopt a style representative of layered analysis (Ronai, 1992, 1995) and employ the use of asterisks (***) to signify a change in *voice.*

Chapter 2

INTRODUCTION

Hospice, the organizational and philosophical concept of care designed to provide comfort and support to terminally ill individuals and their families, is garnering a great deal of interest within organizational health communication, in both theory and praxis. Due in part to substantive demographic changes taking place in the United States and the rapid growth of an aging population, hospice has become a ubiquitous component of the medical community. As evidence, we can look at a study recently conducted by researchers at the RAND Corporation in which they reported not only the ways in which most Americans can expect to die, but stated that longer life spans mean "nearly all elderly Americans now encounter sever chronic illness and disability in the last phase of life" (Lynn & Adamson, 2003, p. 1). Given this data, it seems likely that most people either have or will encounter hospice at some time or another in their lives—if not for themselves, for someone they love.

These health and demographic statistics undoubtedly contribute to government projections indicating that healthcare is expected to generate more new jobs than any other industry in America until at least 2018 (Bureau of Labor Statistics, 2010). Yet, somewhat alarming, the U.S. Department of Health and Human Services recently released the findings of a survey that was conducted on one component of American worker's well-being: depression (*NSDUH Report*, 2007). Organized by occupational category, the survey revealed that individuals who worked in personal care, social services, and healthcare—fields directly charged with the care of the ill and/or aging, as hospice workers are categorized—experienced the highest rates of depression of all US workers. While we cannot (and should not) assume a cause and effect relationship between occupation and mental state, what is evident is that end-of-life issues are extremely complex and clearly necessitate further attention.

For example, as the Health and Human Services report states, depression seriously impacts a person’s ability to perform their job and costs businesses billions of dollars per year. Yet lost in this cursory summary are many other unidentified implications, such as the impact a worker’s overall mental health has on the individuals that are the focus of their jobs. And while the numbers of workers (approximately 10%) in these fields experience more major depressive episodes than other job categories, we could surmise that roughly 90% of them do not, and many of them may actually experience great joy and satisfaction in their work. In fact, hospice workers constitute one healthcare specialty that continues to report very high job satisfaction rates (Brenner, 1997; Qaseem, Shea, Connor & Casarett, 2007). Thus, we could ask about both the emotional highs and lows of hospice work as a means to understand why and how individuals keep from experiencing loss of pleasure from their jobs and what might contribute to overall job satisfaction.

At the same time as the various government agencies and funded studies have alerted us to these potentially problematic demographic, health and occupational hazards and concerns, organizational scholars have undertaken a shift in research focus as well. A number of researchers and scholars have now moved away from focusing on the purely negative aspects of workplace processes, such as stress and burnout, to trying to understand and incorporate the positive aspects of organizational life. Compassion is one such area that is garnering interest within organizational studies, with scholars suggesting that workers who are engaged in compassion work—as hospice workers do—may, in fact, experience great joy and fulfillment in their professional lives. Clearly, the ways in which hospice and compassion intersect constitute one area of organizational health communication that is rife with research possibilities.

An increasing number of scholars across academic disciplines have embraced the study of health related theory, research and practice (Harter, Japp & Beck, 2005). The same can be said within communication studies. Health communication is now the rubric under which the interdisciplinary nature of health care related issues has become apparent within the human communication discipline. For instance, organizational communication scholars may study the institutional changes within the organization of health care, such as the shift to managed care (e.g., Apker, 2001; Lammers & Duggan, 2002; Lammers & Geist, 1997), interpersonal communication scholars may study physician-patient communication in light of such a shift (e.g., Ledlow, O'Hair & Moore, 2003; Sharf, 1990; Street & Millay, 2001), and rhetoricians and critical scholars may be concerned with uncovering the power implications of the shift toward a model of health care that requires the patient to "discipline" themselves (e.g., Bates, 2005; Foucault, 1973; McDorman, 2005; Sharf & Street, 1997). Clearly, the depth and breadth to which communication scholars have embraced the study of health and illness over the past decade(s) are evidenced in our journals; rarely does a volume not reference some health and/or illness related topic.

With regard to communication studies and hospice, however, the body of literature thins dramatically. For example, when conducting an online search of academic databases and using the search terms "hospice" and "communication studies," thirty-four citations arise. Admittedly, this method will not produce, and is not indicative of, all the research published on the topic. It is, nonetheless, an indicator that we are not saturated with studies on this topic. And although there are a number of academic journals dedicated to hospice, the majority of the research published in them emanates from the fields of social work, sociology, gerontology, nursing, and medicine. Of the hospice research that has been produced by communication scholars (regardless of journal type), recent studies have focused on hospice volunteers (Egbert & Parrott, 2003; McKee, Kelley & Guirguis-Younger, 2007), communication in hospice interdisciplinary teams (Wittenberg-Lyles, Oliver, Demiris, G, et al., 2008, 2009), hospice caregiver support (Egbert, 2003), and spirituality in hospice (Considine, 2007). When it comes to hospice workers and issues of emotion—such as compassion or other aspects of positive organizational communication —there is essentially no published research available.

Mediating End-of Life Care

While the concept of hospice has been evolving for nearly a thousand years, a genealogy of the modern hospice movement reveals that specialized care for dying individuals first appeared in the United States in 1974. Hospice originated as an ideological movement from within the medical community, and its leaders advocated for the use of new techniques that would keep the dying relatively free from pain (Levy, 1989). Abandoning the traditional forms of terminal care that encouraged the use of frequently futile measures to prolong life, hospice methods gave the dying greater control over their medical care, and hence their daily existence as well. Deemed *death with dignity*, hospice ideology embraced a holistic approach in supporting both an individual's physical and psychosocial needs, treating the dying individual and her family as the central unit of care.

Although the majority of care, 96%, takes place in the home (NHPCO, 2007), a substantial percentage of hospices operate at least one inpatient unit for individuals to come when either their symptoms cannot be managed in the home, or for respite care so that their caregiver may have a rest. Organizationally, almost 49% of hospices are nonprofit while for-profit entities represent 46% of the sector. Another 5% are operated by the government. Regardless of ownership type, hospices all deliver essentially the same services: a specially trained team consisting of physicians, nurses, home health aides, social workers, counselors, clergy, and community volunteers develop a care plan tailored to each person based on his or her needs for pain and symptom management. A family member or loved one serves as the primary caregiver and is included in decision making when appropriate.

While hospices have seen a 162% increase in patient services over the past 10 years alone (NHPCO, 2007), the fact that 80 million baby-boomers will reach retirement age between 2008 and 2028 (*Nations first*, 2007) is merely one factor contributing to the likelihood that the demand for hospice care will grow exponentially in the coming decades. Dramatic changes in the organization and status of health care in the U.S., increasing life spans, changing patterns of illness and chronic disease, and skepticism of medical authority, will also prove to enhance the desirability of hospice in the coming years.

Likewise, as hospice patient care increases so too will the hospice workforce. In the past five years alone, the number of staff employed by Medicare-certified hospices has nearly doubled (Qaseem et al., 2007). And while there is a robust body of literature from a number of academic disciplines that explores worker satisfaction and well-being in a number of occupational categories (some of which will be reviewed in the following chapter), there is substantially less research focusing on hospice workers. In fact, researchers at the University of Pennsylvania, in conjunction with the National Hospice and Palliative Care Organization, have just recently initiated the first ever job satisfaction survey designed specifically for the hospice field, the initial results of which will not be available until early 2009. This dissertation contributes to better understanding an ever growing group of employees, which remain largely an enigma.

Motivations: Past, Present and Future

The impetus for this study was twofold. The first is my own family experience with hospice when my mother died in February 1998 from lung cancer. The second is health communication research I conducted with a hospice agency; In 2002—four years after my mother's death—I conducted my first ethnographic study within a hospice agency, the focus of which was the emotion management strategies of hospice nurses (Way, 2004). As my narrative foreshadowed in the previous chapter, my experience as a hospice services recipient led me to want to understand how it was that nurses were able to engage in what I believed to be extremely demanding emotional work. From that study I discovered many, if not most, nurses contested the idea that their jobs were excessively (or negatively) laden with emotion. On the contrary, the nurses often stated that they found the work enjoyable and fulfilling. Still skeptical that the workers weren't engaging in a great deal of emotion management, however, I continued my hospice research believing that, perhaps, hospice workers' emotions lurk latently beneath the surface waiting to emerge. It wasn't until several years into my emersion in the field that I recognized a change in my own experiences of emotion, as well as my feelings and attitudes about death and dying. Once I began to encounter death and dying not with a sense of fear and dread, but with calmness, I felt my emotions transform from anxiousness to understanding and acceptance. As data emerged through my first and second study, coupled with my own experience(s), I began to realize that in order to really understand the emotional experience of hospice, I would need to broaden the scope of my research agenda—the literature on emotional labor alone was not sufficient for best understanding emotion in the hospice workplace or my personal experience.

For example, according to the extant emotional labor and burnout literature, my change in perspective on death and dying was akin to “depersonalization.” In short, depersonalization, a concept I will discuss in more detail in my literature review, is theorized as one component of burnout. In contrast, I felt like the change was more akin to "normalization"--a positive thing. My assessment about how this transformation was really a positive thing, though, could not be adequately explained by the emotional labor and burnout literatures. One day, as I was riding along with a social worker as she made her home visits, I asked her what her perspective was on death, given that no one that I had yet encountered in hospice either feared death and dying, or seemed to be burned out. I was recording our conversations in the car that day:

> ME: When I first started volunteering at Avenida Sur and I would do my work and go home and have my laptop in my car and I’d go to a coffee shop and write my fieldnotes after I left, you know, right away to get everything down. When I first started working, there were so many times I would find myself on the verge of tears. Like things would really touch me and I would find a lot of things that were really poignant. Over time the same circumstances or types of incidences wouldn’t bring me to tears. And my advisor would say, well, what you are describing is a symptom of burnout. And I would say, it’s not burnout. I only volunteer four hours a week. I’m not burnt out. She said, well desensitization is a symptom of burnout. I would say, I know the feeling and I know it’s not burnout. I’m not there enough to be burned out. I can come and go as I please…I’m not, you know, I’m not an employee. I have the option of being there or not. It’s not depersonalization! And I have a hard time getting that across to

> people who don’t understand. What do you think? Do you or have you had similar experiences? Do you know what I’m talking about?
>
> SARAH: Oh sure!!I don’t want to deny the value of having emotion because that’s what connects us as human beings. But you know, you don’t keep the rawness. You know, it’s kind of like the heart gets stronger…I’m using the heart as a metaphor to get at the idea of the interior level of understanding. You allow the heart to open…you allow the heart to evolve and it’s like an emotional muscle and it doesn’t have to be collapsing into tears every time there’s a poignant moment. You can keep a sense of awareness in all things. It really comes back to that whole notion of suffering. Suffering can ground us, suffering can help us find meaning. Suffering is something to push off against so that you can stretch and grow. For every developmental stage in life you need something to push off against. Once you get that, and step out of the drama around it and just start honoring the person’s process, you lose a lot of this superficial emotionality. I don’t think it is depersonalization…I think of it as normalization. It is normal and healthy and appropriate to be involved in the fluidity of life. Life is fluid, why must we attach these negative labels to everything instead of trying to understand how the frame has changed.

This day and this conversation marked the point at which I began to envision a broader range of research possibilities. I now wanted a more detailed understanding of the emotional highs and lows of hospice work. What emerged from my research, and seemed to play a role in mitigating at least some of the emotional lows that hospice workers experience, was the importance of compassion. In fact, it appeared that compassion could very well serve as an emotional high for some hospice workers. These preliminary findings encouraged me to delve into a body of newly emerging communication literature and research—positive organizational communication. Thus, based on the summation of my past and present academic and personal experiences, I came to believe that this project had future transformative potential in both theory and practice.

The overarching goal for this dissertation is to expand the body of research in organizational health communication through an analysis of hospice worker narratives, specifically focusing on the ways in which workers make sense of the emotional highs and lows of their work (Lawler, 2002). While the body of research in health communication is growing rapidly, most of the existing research on hospice workers is quantitative and comes from the nursing and social work fields. Therefore, this project has the potential to begin filling a critical gap within communication studies. The remainder of this chapter teases out some of these ideas, as well as maps the trajectory the project takes, and concludes with my research agenda.

Sensitizing Concepts

It is important at this point, prior to previewing the motivating literature, to reiterate the emergent nature of this project. As noted previously, my first hospice study was firmly grounded in the literature of emotional labor. The data collected from that study provided many rich and detailed narratives of emotion management, as well as experiences of compassion—positive and negative—for this study as well. It was through my subsequent years of research and emersion in the hospice field that I realized what I was experiencing, seeing, and hearing may include concepts and theories beyond stress, burnout and emotional labor—the primary topics related to emotion that afforded attention by communication scholars.

Given my preliminary analyses and pilot data, it made sense to enter the larger study, still with an understanding of stress, burnout and emotional labor in hand, but also with an understanding of compassion. It is of my belief, based on my final analyses, that at least with regard to hospice, you can't fully consider and understand the negative emotions without considering and understanding the more positive emotions. Let me explain.

Consistent with grounded theory and analysis, a concept which I fully explicate in chapter four on methods, I did not directly address issues of compassion in my interviews—it was but one of a number of themes that emerged from the data, and which later emerged as a central theoretical category. My sensitizing questions pertained to the emotional highs and lows of hospice work, not any one specific aspect of those highs and lows. I knew that hospice workers (potentially) experienced both positives/highs and negatives/lows in their jobs and I was open to either, neither, or both. Appendix B contains the interview protocol that guided my research, and although some workers were directly asked, "What does compassion mean," "How do you convey compassion," and "How do you know if someone is suffering," these were not preconceived or predetermined concepts. Instead, they were asked as a means help sift through what might be the hospice ideology for which workers are often enculturated.

Hospice is not only a workplace, it is an ideology about death and dying (which I discuss in greater detail in the following chapter). At times I wasn't sure if what a worker was telling me was what she/he really thought or felt, or if it was a 'knee-jerk' response of hospice rhetoric. I felt that asking as many similar questions in as many different ways as I could, would help me get to the core of their beliefs. For example, I asked one worker if she felt she had changed in any way since working in hospice and she told me yes, that she was more compassionate now. When I asked her what compassion meant to her, she said, "giving all you've got with no strings attached." Yet, when I asked her to tell me a story about a time when she felt especially appreciated by a client, she told me she rarely feels appreciated and has considered leaving because of that. Had I stopped with the first two questions, I would not have gotten at the complexity and depth of her feelings about the compassion demands of her job. In other words, the multiple questions helped reveal various facets of the issue—rather than just displaying a singular view that was likely highly influenced by the rhetoric of hospice ideology. From this workers response, I was able to glean both positive and negative aspects of her job.

Therefore, while the research questions that I propose at the end of the following chapter (chapter three) address processes of compassion, I also address the potential barriers to compassion that workers describe. With these factors in mind, the scope of this project called for my literature review to ultimately trace this study’s emergent path—which demands understanding the extant research on burnout and emotional labor, but also taking a foray into research on compassion and positive organizational scholarship. What follows now is a preview of the literature that guided this journey, and which will be discussed in greater detail in the literature review.

Workplace Discourses

Although the next chapter will detail the literature on emotion, stress and burnout, and compassion in organizational contexts, it is nonetheless worthwhile to provide a brief overview of some of the motivating literature in this introductory chapter. Prior organizational research has been dominated by studies about negative organizational processes, which are not as helpful for shedding light on the compassion component of hospice work and hospice workers. A recent addition to the way in which we study organizations, however, has been through a shift in focus from the purely negative, to incorporating positive aspects of organizational life, as scholars did when they suggested that compassion might very well not be a source of stress, but a source of great fulfillment. Hence, this study lays its foundation on the extensive body of empirical research on stress and burnout, emotional labor and compassion fatigue, and then builds on positive organizational studies. Research on compassion—one of the newest areas of organizational communication studies—reveals that it is a positive force, which is “an essential, yet often overlooked aspect of life in organizations” (Kanov, Maitlis, Worline, Dutton, Frost & Lilius, 2004, p. 809).

Stress and Burnout

Americans log many more hours per week in employment than their European counterparts (Alesina, Glaeser & Sacerdote, 2005). Thus, it is little surprise that stress and burnout are major problems not only for employees, but for their employers as well. And the growth in the stress and burnout literature attests to the “destructive dimensions of organizational life” (Tracy, 2009). Although stress and burnout are two distinct processes and products, the two concepts are frequently studied in tandem, with the assumption that that occupational stressors (such as emotional work or labor) can lead to burnout. Overall, healthcare is a field with substantial emotional demands and occupational stresses. And yet, while studies often acknowledge the emotional labor required of nurses (James, 1989, 1992), disagreement exists as to whether hospice nursing is more or less stressful than that of other nurses (Payne, 2001; Sherman, 2004).

Emotional Labor

Scholars assert that one of the major contributors to stress and burnout in the workplace is emotional labor. Arlie Hochschild (1983) is the person most frequently accredited with launching the study of emotional labor—labor performed for wages that require either inducing or suppressing displays of emotion in order to present the right appearance—nearly 25 years ago, and scholars are still actively pursuing and extending its application. Hochschild originally studied flight attendants, but emotional labor has been theorized in a variety of diverse organizational contexts, such as in the study of 911 call takers (Tracy & Tracy, 1998), correctional officers (Tracy, 2004, 2005), firefighters

(Scott & Meyers, 2005), cruise ship workers (Tracy, 2000), female inmates (Greer, 2002), and doctors and nurses in a cardiac care unit (Morgan & Krone, 2001). A number of researchers have also aptly noted the distinction between emotional labor and emotional work (Miller, Considine & Garner, 2007; Tracy & Tracy, 1998). That is, not all emotion is inauthentic and/or organizationally mandated. Sometimes the work itself is emotional. This is especially true for health care, which, needless to say, can be extremely emotional work. In fact, Hunter and Smith (2007) fear that 'emotional labor' has merely become a 'buzz word' within health care research, which has resulted in little actual change in structures, processes or outcomes within health care.

Compassion

Compassion fatigue constitutes a large body of research that evolved from the field of traumatology and a focus on occupations in which individuals witness suffering, such as is the case with nursing (Abendroth & Flannery, 2006) and mental health (Becvar, 2003; Collins & Long, 2003). In the same way that Hochschild is credited with founding emotional labor studies, sociologist Charles Figley (1995) led the charge in compassion studies. Compassion fatigue is described as a form of secondary traumatic stress associated with the 'cost of caring' for people in emotional pain (Figley, 2002). Individuals who enter occupations such as hospice often do so out of a desire to help others or 'make a difference.' In this capacity, workers connect and empathize with their clients, and scholars caution that when "our hearts go out to our clients through our sustained compassion, our hearts can *give* out from fatigue" (Radey & Figley, 2007). Scholars argue that compassion fatigue is a detriment to worker well-being and often a precursor to burnout (Collins & Long, 2003; Hilliard, 2006).

Positive Organizational Studies (POS)

One of the newest and most enlightening additions to the field of organizational studies is POS. Two researchers at the University of Michigan aptly summarized the need for a paradigmatic shift in the way we think about workplace relationships and organizational discourse:

> Psychologist Abraham Maslow has been apocryphally credited with an observation that summarizes our paper. Maslow noted that 'if the only tool you have is a hammer, you tend to see every problem as a nail.' The claim is that familiarity and practice influence our perceptions, and that we tend to understand the world in ways that conform to our available means. However, problems arise when those means do not suit the problem, when a hammer-wielder is confronted by something other than a nail. We argue that the disciplinary tendency toward paradigmatic assumptions has affected organizational science in a fashion similar to providing a toolbox with only a hammer in it, and that Positive Organizational Scholarship (POS) can serve as an additional tool (Barker Caza & Caza, 2005, p.3)

Researchers who have taken up the call for POS argue that although organizations can be the site of stress, anxiety, pain and suffering, or places where the 'necessary evils' of work take place (Lilius, Worline, Maitlis, Kanov, Dutton & Frost, 2008), it is time to shift our focus to the many positive aspects of organizational life. Radey and Figley (2007) advocate for a move away from researching the negative consequences of work life, to identifying what it is that leads workers to thrive in their fields. For instance, not all caregivers succumb to the secondary traumatic stress of compassion fatigue; hence, there must be a protective mechanism that helps maintain the caregivers’ well-being (Stamm, 2002). A caregivers’ motivation to help is shaped in part by the satisfaction derived from the work of helping others. In this fashion, a number of scholars are looking at compassion satisfaction and the ways in which compassion functions as a positive attribute of one’s job (Collins & Long, 2003).

Research Agenda

Considering the preceding information, the purposes of this study are multiple. First and foremost, this study contributes to what is currently a rather thin body of research on hospice workers from within the communication discipline. As previously noted, most of the existing literature comes from the nursing, sociology, psychology, and social work arenas. Although the existing body of research is impressive and noteworthy, it is clearly time for organizational and health communication scholars to take notice of the burgeoning hospice field—in anticipation of 80 million Americans beginning to retire. Additionally, this study answers the call posed by organizational behavioral scholars to consider not only the negative processes at work in organizations, but also the positive aspects of organizational life. As was demonstrated in my early research, as well as through this study, not all hospice workers experience stress, burnout, or compassion fatigue, and in fact, many (if not most) experience a great deal of compassion satisfaction. While it is not until the following chapter that my research questions are formally posed, the guiding focus of this dissertation will be on the stories hospice workers tell. What are the narratives that workers tell about the emotional highs and lows of their jobs? How do the narratives compare and contrast?

Second, because a substantial portion of the existing emotion research, especially that related to emotional satisfaction, stress and burnout, has been generated through quantitative methods, this study offers an in-depth understanding through qualitative methods that include participant observation and in-depth interviews. As Tracy (2009) notes, we need to move away from the ‘box and arrow’ diagrams that punctuate much of the current organizational research on stress and burnout and make a move towards understanding *how* the boxes were constructed and what happens in between them. Specifically, I privilege the narratives of the hospice workers themselves as a method of understanding experience(s) of compassion. Exploring compassion though a narrative lens allows researchers to consider “the micro-moves that happen as people, individually and collectively, ‘work the context’ to create a compassionate response” (Frost, Dutton, Maitlis, Lilius, Kanov & Worline, 2005, p. 851). As Garro and Mattingly (2000) convincingly argue, “Narrative is a fundamental human way of giving meaning to experience. In both telling and interpreting experiences, narrative mediates between an inner world of thought-feeling and an outer world of observable actions and states of affairs” (p. 1).

Summary

In this chapter I have outlined the theoretic parameters that underpin this project. Specifically, I have provided a broad overview of the current state of health communication research within communication studies, and provided a brief overview of the modern hospice movement. Then, I identified my own motivations for this study, and provided an initial overview of the organizational scholarship that orients this project, all of which will be covered in greater detail in the next chapter. And finally, I formally proposed my research agenda. In the next chapter, I turn to a review of the literature that frames this study and formally present my research questions.

Chapter 3

LITERATURE REVIEW

This dissertation engages literature from a number of academic disciplines with the intent of expanding the way we think and talk about worker's emotional health and well-being. Specifically, I am interested the ways hospice workers narrate the emotional highs and lows of their jobs. Chapter two is divided into five sections and proceeds as follows. First, I provide a more nuanced look at hospice as both an organization and an ideology. The dynamics of hospice and hospice work will clearly influence the ways in which workers experience their jobs. Next, I consider the organizational discourses that theorize the harmful aspects and negative consequences of work. Specifically, I review the literature on stress and burnout, paying particular attention to how emotional labor may potentially contribute to burnout. A great deal of attention has been given to the detrimental effects of stress and burnout, for both the individual and the organization, and suffice it to say, the depth and breadth of research that exists on stress, burnout, and emotion, fills volumes of journals and books. My intent here is to review the seminal research, which further contributes to our understanding of the nature of hospice work. Interestingly, however, some research suggests that hospice workers do not experience the rates of burnout that other occupational healthcare groups do, which begs the question of why this may be and what factors may lead to their emotional well-being.

In the third section, I move from the literature on negative organizational processes to trace the shift in organizational studies from negative to positive.

Positive scholarship is a new area of inquiry that seeks a new way to look at old phenomena. Positive organizational scholarship challenges the predominantly negative assumptions about organizational life that have been the norm in organizational studies. Positive scholarship focuses on the dynamics that lead to exceptional individual and organizational performance, and is the generative theory guiding this dissertation.

In the fourth section I introduce the concept of compassion and provide a review of the literature on compassion and work. While most of the literature on stress and burnout focuses on its negative organizational effects, the literature on compassion fatigue and compassion satisfaction considers a constellation of effects, from organizational outcomes to the long-term personal consequences and rewards of dealing with people in crisis. While research on caregiver well-being has, until very recently, focused almost entirely on the negative costs of caring, the addition of the compassion satisfaction construct is an important step towards understanding the positive aspects of hospice work. In the fifth and final section I restate my research focus and formally present my research questions.

Hospice and Palliative Care

Hospice is an integral component of this dissertation for several reasons, first and foremost because of my personal experience with hospice. But second, in light of the demographic changes discussed in the previous chapter, hospice has become a ubiquitous component of the medical community. And while I provided an overview of hospice in the previous chapter, it is nonetheless important to further discuss hospice ideology and the organizational dynamics that contribute to hospice culture, and hence, the way in which hospice workers may think and talk about their jobs. It is also important to note that the claims, notions, and discourse(s) regarding death, dying and hospice that I discuss and which ground my research, refer and apply to death, dying and hospice in America. The ways in which cultures across the globe view death and dying, and the ways in which cultures think about and organize hospice care, can vary dramatically from the United States.

Hospice/client and hospice/physician dynamics

Evidence from numerous studies show that, when considering their final days, people prefer to die at home, free of pain, and surrounded by their loved ones (Hayslip & Peveto, 2005; Kastenbaum, 2004; Lynn & Adamson, 2003; Seale, 1991; Van Der Kloot Meijburg, 2005). Yet despite the rise in the number of hospice programs nationwide, approximately 65% of all Americans die in hospitals and nursing homes (NHPCO, *Facts and Figures*, 2007), institutions that are often ill prepared to offer individuals the kind of care they most need at the end of life. Attesting to the benefits of hospice care are numerous studies supporting the contention that families, caregivers, and terminally ill individuals express great satisfaction with the quality of care and support they receive from hospice (Connor, Tenno, Spence & Smith, 2005; Greer, Mor, Morris, Sherwood, Kidder & Birnbaum, 1986; Kaasa & Loge, 2002; Lynn, 2001; Seale, 1991). In contrast, studies show that individuals entering hospice at late stages of their disease suffer unnecessary and multiple symptoms of distress (Woods, Craig & Dereng, 2005), and their families report lower satisfaction with care and higher rates of unmet needs (Schockett, Teno, Miller & Stuart, 2005). Thus, hospice personnel believe, and many families agree, that late entry into a hospice program hinders their ability to provide the services necessary to facilitate a "good death."

Additionally, the continued decline in the length of stay by individuals at hospices has intensified friction between two hospice stakeholders: physicians who are responsible for referring clients to hospice, and the hospice leaders themselves. Statistics indicate that the terminally ill are entering hospice programs closer to their time of death than in previous years. The NHPCO (2007) reports that the median length of service is only 20.6 days, with 35% of hospice clients dying in seven days or less. Hospice directors frequently blame physicians and the medical community at large for late referrals, stating that it is not in the best interest of the individuals, their families, or hospice workers when their clients enter in such advanced stages of dying and multiple symptoms of distress are more difficult to control.

Conversely, however, physicians argue that as long as a patient expresses a desire to undertake curative measures, it is their duty to provide whatever form of treatment the patient wants—regardless of whether they believe their client will benefit from those measures or not. And because research indicates that an ethos of fear and anxiety infuses American attitudes toward death and dying (Hayslip & Peveto, 2005; Neimeyer, Wittkowski & Moser, 2004), clearly, not all the blame for late referral can be attributed to doctors—many individuals actively pursue even the most unpleasant treatments in the search for a miracle cure, even when they know it will likely prove fruitless. As one hospice nurse I talked to stated, "I don’t know why people insist on finding a cure for everything! Don’t they know their remaining lives would be much happier if they would just accept their diagnosis?” Her remark clearly reflects one of the many complex dynamics of hospice work, where workers are responsible for making their patient’s final months and days as comfortable as possible.

Another recent trend in the hospice movement is the addition of separate palliative care units. Because the length of time from the onset of a serious disability to the time of death can often be measured in years, not days or weeks as was the norm at the beginning of the 20th century, individuals who suffer from chronic illness often find that their diseases can manifest in multiple and ambiguous medical prognosis, leading to a period of “dying” that can span years. Therefore, symptom management and support services are no longer restricted to those with a relatively short and easily definable end-of-life period (Lynn & Adamson, 2003). While palliative care is and has always been the primary service provided by hospices, palliative care providers—often a separate program or service provided by a hospice—work to improve the quality of a seriously ill person’s life. And while the distinction between the two can be confusing and the terms ‘hospice’ and ‘palliative care’ often used interchangeably, palliative care units provide care for the seriously ill, regardless of life expectancy, and permit the continued use of curative treatments. Hospice care, meanwhile, is for those with a life expectancy measure of months, not years, and only allows for medicine and treatments that focus on alleviating symptoms.

Hospice Ideology and the Good Death

Not only does the concept of the *good death* pervade a great deal of the popular literature on death and dying, it is central to the ideology of the modern hospice movement. However, over the past fifty years the term has gained a near mythical status all its own. And most individuals (if not all) would likely say a *good death* is what they want when they die. Yet, if asked what a *good death* means to them, no two individuals' answers would likely be the same. The good death is not a fixed-point single event, but a complex, context dependent set of relations and preparations. While it may be the individual who dies, the experience of death and dying involves a number of people and institutions, from physicians and health care providers, to friends and family (McNamara, Waddell & Colvin, 1994).

Although historian Philippe Aries' (1974) accounts of death and dying from the Middle Ages to the mid-twentieth century reveal that there has almost always been a "good" way to die, it was thanatologist Avery Weisman in 1972 who first proposed the concept of the *appropriate death*. According to Weisman, an appropriate death is purposeful, pain-free, and with as little emotional distress as possible. What may be considered an appropriate death to one individual, Weisman stresses, may not be considered appropriate to another. Yet, it was the broad appeal of Elizabeth Kübler-Ross' (1969) work that contributed to the ideology of the *good—a*nd *bad—d*eath. In Kübler-Ross's stage theory, the final stage of acceptance became the goal of many who were providing care for the dying. As evidence, much of the nursing literature promotes Kübler-Ross' stage theory as the model of care for the dying, a model in which the "angry, nonaccepting and non-compliant patients become deviants who are violating the established norm” (Hart, Sainsbury & Short, 1998, p. 69).

Complicating the ideology of the good death is the array of divergent responses in which there can be distinct differences between how a dying individual conceptualizes the good death, and the ways in which families, friends, and medical personnel do. Although there is much literature on “good” and “bad” death based primarily on the experiences of hospice personnel, the question of what constitutes a good death remains largely unanswered. For instance, researchers found that hospice nurses focus more on the death itself, rather than the dying process (Costello, 2006). Good and bad deaths were more the result of the death event and nurses’ ability to manage organizational demands, and less the dying persons’ needs. While nurses wanted individuals to die without distress, that included not wanting distress for themselves either. Likewise, health caregivers define a good death as one in which there is not only patient awareness, acceptance and preparation for death, and a calm, dignified dying, but one in which the nurses are comfortable with the events and interactions as well (McNamara *et al* 1994, 1995). Bad deaths were those that did not fulfill the caregiver’s criteria.

Conversely, dying individuals perceptions of a good death are often quite different from those of their caregivers (Masson, 2002). Dying individuals can often conceive of the notion of a dynamic, rather than static, good death ideal. These individuals are able to renegotiate what a good death means to them in light of ever-changing conditions and limitations. Masson (2002) makes an argument for the concept of a “good enough death” which he believes would better encompass this ongoing negotiation process. The “good enough death” is, “one where people strive together to get as near as possible to a death which *positively coheres* with, or *positively contradicts*, the life of the dying person” (p. 208). Because no matter how skilled or humane our care of the dying is, “it does not, and cannot ‘make it all better’” (Kearney, 1996, p. 207).

Ultimately, critiques of the good death ideology ask us to consider who it is that benefits from the good death. What has discursively emerged is an ideology “that upholds the ideals of dying with dignity, peacefulness, preparedness, awareness, adjustment and acceptance” (Hart *et al*., 1998, p. 72). And while a laudable goal, what it reveals is a socially constructed and prescribed form of death and dying with clearly defined modes of behavior. However, we should not privilege “expressive individualism” either (MacKendrick, 2005). The postmodern sovereign individual, who is required to make autonomous decisions regarding her care, is the paradoxical alternative to religious and medical authority—“authority of the self” does nothing to change or challenge the nature of traditional authority. While the norm of requiring a good death has certain advantages, it has disadvantages as well. As Walter (1994) notes, “it is not so much that I have decided to do it my way: I am being required to” (p. 37). Clearly, in the politics of care, the choices and opportunities available to dying individuals are both shaped and constrained by those who care for them.

Cultural Critiques

Although most agree that hospice provides a much needed, wanted, and respected service, it has not been without critique. Having grown from a philosophical grassroots movement to a multi-million dollar industry in a relatively short period of time, it is not surprising that accolades have been tempered by a number of scholarly critiques. For instance, in tracing the evolution of hospice in America, researchers note that as hospice has evolved from a loosely organized reform movement to one with a well defined organizational structure, the resulting homogeneity not only between individual hospices, but between hospices and other health care organizations, is much like “other reform-oriented movements [which] eventually became much like the institutions they sought to change” (Paradis & Cummings, 1986, p. 371). This isomorphism resulted from increasing dependence on federal, state and private reimbursement that required hospices to conform to their funders requests. Additionally, Medicare, the predominant funding agency, tells hospices what types of staff they must have, their professional qualifications, and the types of services they can and cannot offer. Hence, hospices hire staff they have recruited from the mainstream medical community, and along with them they bring the mainstream medical ideology and discourse to which they have been enculturated. This bureaucratic structure means that there is little room for innovation and creativity (Paradis & Cummings, 1986).

Furthermore, critics admonish, the institutionalization of the hospice movement has resulted in shifts in hospice’s founding ideals. Most hospice discourse emphasizes the uniqueness of the dying person, stating that the individual is free to define the terms of his or her own death and dying. Yet, the original *death with dignity* mantra that the early hospice movement espoused has become inextricably linked with modern notions of a *good death*. As noted previously, critics warn that the idea of a good death has itself assumed a socially sanctioned mythical status, and prescribes a less than value-free role to which the dying must now conform (Masson, 2002). Far from being a single event, the good death is now considered a series of social events that involve patients, their families and friends, as well as medical professionals (McNamara *et al*., 1994). The good death ideology operates as a system of social management within hospice, leading to the labeling of patients as either *good* or *bad* (Hart *et al*, 1998). The good death construct operates as a coping strategy for those working in hospices (McNamara *et al*, 1995). Placing dying within an idealized context helps to alleviate anxiety and provide structure and routine. However, regardless of the reasons, the institutionalization of the “good death” clearly has the power to significantly constrain the choices of dying individuals.

Hospice workers and hospice work

While the specific employee demographics of each individual hospice will vary to some degree, for all the reasons mentioned above (Medicare requirements, organizational homogeneity, etc.), there are more similarities than differences between similar sized organizations. According to the NHPCO (2007), nearly 77% of all hospice employees are involved in direct patient care. Nurses constitute the largest percentage of full-time staff, while paid physicians (some physicians may be on staff and unpaid) represent the smallest percentage.

Additionally, as is mandated by Medicare, volunteers account for 5% of all staff hours.

Before moving on to a detailed discussion of the theoretical models and concepts that frame this study, it is important to understand the nature of hospice work. While hospice workers *are* healthcare workers, healthcare alone doesn't adequately describe the scope or significance of the labor they perform. Hospice workers provide a service that is often stigmatized (working with the terminally ill) yet highly valuable to society. As such, it is important to contextualize hospice work within the field of human services.

Although there are a wider range of occupations that fall within the category of human service work—from doctors and nurses, to teachers, child care providers, and ministers—they can be distinguished from other service jobs because the primary goal is to mediate and/or provide for the daily care of a person in need. Whether the services provided are physical or psychological, the presumed goal is a change for the better (Dollard, Dormann, Boyd, Winefield & Winefield, 2003). In hospice work, change for the better entails not curing, but attempting to ameliorate *both* the physical and psychological discomforts of illness and dying. In this way, their jobs require "the mental, emotional, and physical effort involved in looking after, responding to, and supporting others" (Baines, Evans & Neysmith, 1991, p. 11).

Human service work entails a high degree of interaction between the worker and the client (Miller, Birkholt, Scott & Stage, 1995). Additionally, there is usually no quality control in between the two. Dollard *et al*., (2003) refer to this as the *uno acto* principle in which the service provider has but one opportunity to provide an excellent service—the wrong medication or an unnecessary surgery may require a ‘repair’ which, from the client’s viewpoint, will negate the original service. Each employee has total responsibility for the quality of their work and the satisfactory delivery of that service. Consequently, there is a high degree of both risk and responsibility. Human service jobs are those in which “tangible products are of minor importance compared to the “experiences” customers receive” (Dollard *et al*., 2003).

Employee-client communication in hospice is often emotionally charged, with caregivers being responsible for providing for the needs of people who are living through extremely difficult experiences. Caregivers share three characteristics: their work is emotionally demanding, they have exceptionally great empathy towards others, and their industries are characterized as client-centered where the only legitimate feelings are those expressed by clients (Malakh-Pines, Aronson &Kafry, 1981). Caregiving involves not just caring *for* someone, but caring *about* someone as well (Ungerson, 1983). Taken together, these factors have clearly contributed to the growing body of literature on emotion, stress and burnout in the human services and healthcare industries.

This project will draw upon the narratives of hospice workers who are involved in direct patient care in a number of job categories, including 1) nurses, 2) nursing assistants, 3) social workers, and 4) spiritual care providers. As this chapter progresses and various strands of literature are reviewed, whenever possible, I will incorporate literature which specifically addresses any and/or all of these occupational groups. It is worth noting, however sadly, there is scant research on nursing assistants. An alarming example of this is evident when conducting a cursory search on EBSCO with the key search terms ‘nursing assistants’ and ‘hospice’ and a mere 24 hits arise. Replacing ‘nursing assistant’ with ‘nurse’ nets an excess of 2900 hits, ‘social worker’ nets 432 hits, and ‘spiritual care advisor or chaplain’ brings in more than 2500 hits. And it is rather surprising that nursing assistants are so understudied given that they are the primary institutional caregivers in hospice and palliative care, providing up to 90% of hands-on patient care (Sidwell, Ersek, Kestner & Kraybill, 2005). They also have one of the highest job turnover rates in healthcare. Nursing assistants receive extremely low wages, perform heavy workloads, and tend to endure substantial lack of recognition and respect (Fitzpatrick, 2002).[1] And while there is considerably more research on nursing assistants in other organizational settings, such as long-term care facilities like nursing homes, than in hospice, it is still paltry in comparison to the literature on other healthcare and human service workers. The relative lack of research on the lowest tiered level of nurses, while unfortunate, should perhaps be unsurprising. Although there are notable exceptions (e.g., Tracy’s, 2004 correctional officer research, and Mary Romero’s, 2002 book, *Maid in the U.S.A.*), research continues to focus on workers in higher paid occupations than on workers in low-wage, stigmatized, and feminized occupations (England & Folbre, 1999). This dissertation begins to address this imbalance by including nursing assistants in the broader discourses of organizational and health communication.

Negative Organizational Processes

With an understanding of the ideology that frames hospice and the occupational dynamics of hospice work, this section moves on to review the literature on negative workplace discourses. Clearly, the majority of organizational research focuses on the implications for individuals and organizations when workers experience any of the potential workplace stresses. Most importantly, however, a review of the literature on the destructive side of work provides an understanding for how hospice work has been framed in organizational and healthcare research up to this point, providing a sketch of the many contradictions and gaps that currently exist in hospice research.

I begin with a review of the literature on stress and burnout in human services, incorporating a summary of the stress and burnout literature in hospice. As Tracy (2009) acknowledges, “The language of stress and burnout are ubiquitous” (p. 3). Burnout was originally conceptualized as a consequence of the stressors associated with caregiving (Maslach, 1982). Since then, the importance and applicability of stress and burnout to job settings outside of human services has begun to be recognized, thus extending its scope of study. For instance, within the past few years burnout has been examined in a wide array of occupational and social groups once considered outside the realm of burnout because researchers believed that the key factor driving burnout was the intensity of working with emotionally charged clients (e.g., Cressell, 2006; Lingard, Yip, Rowlinson & Kvan, 2007; Reinardy, 2006). Because the majority of stress and burnout research continues to overwhelmingly focus on the human services, and because this dissertation does the same, I will primarily concentrate on the literature in the human service context.

Of particular relevance in framing this section, are the ways in which emotional labor has been conceptualized as contributing to stress and burnout. That is, researchers who assert that hospice workers are stressed and/or burned out often attribute it to the emotion demands of the job. Therefore, I review the seminal emotional labor literature in this section as well.

Stress and Burnout

Hospice and palliative care workers work closely and intensely with seriously ill individuals and their families at highly stressful times in their lives. Tasks and conversations pertaining to end-of-life care cannot be rushed and require a great deal of intellectual and emotional labor (Meier & Beresford, 2006). Hospice social workers are charged not only with determining the logistics of a patients’ care, but are often involved in complex family dynamics that may include unresolved conflicts or unrealistic expectations. Nurses mediate between the patient’s physician, the organization’s administration, and the patient’s physical and emotional needs. Spiritual care providers bare witness to patients’ and family’s innermost fears as they confront the imminence of death. Nursing assistants oversee the day-to-day and hour-by-hour comfort and care of terminally ill people. Any and/or all of these activities can be a source of stress for the hospice employee. Add to this, possible institutional barriers, such as workload demands, cost pressures and bureaucratic constraints, and it would suggest that hospice workers are at high risk of stress and burnout. Interestingly, however, the current literature on hospice does not overwhelming support this contention. In fact, some research suggests that hospice workers are not burned out. What is less clear, however, is *why* they are able to avoid burnout when all the typical characteristics would suggest that they *should* be burned out.

Although the terms ‘stress’ and ‘burnout’ are often conflated or used interchangeably, researchers tend to consider them separate problems and processes. Stress is generally considered an antecedent of burnout. The stress process is described as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984, p.19). While stress may be endemic in many job situations, it is prolonged or chronic work-related stress that can lead to burnout. At a time when service occupations are expected to experience more growth than any other occupational group (*Employment by*, 2007), burnout has emerged as a major concern because it can result in a number of negative consequences for employees, clients, and the organization, such as depression, cynicism, loss of compassion, reduced commitment and turnover (Lee & Ashforth, 1996; Maslach, 1982; Miller, Stiff & Ellis, 1988; Miller *et al*., 1995; Omdahl & O’Donnell, 1999).

The term ‘burnout’ was first coined in reference to a state of physical and emotional depletion resulting from conditions of work (Freudenberger, 1974). Burnout is defined as “a syndrome of emotional exhaustion and cynicism that occurs frequently among individuals who do people-work of some kind” (Maslach & Jackson, 1981, p. 99). It has generally been assumed that the helping professions experience high levels of stress because of the emotional intensity of employee-client relationships (Cordes & Dougherty, 1993). Burnout is best understood as a process, not an event, and is contingent upon individual, work-related, and socioeconomic factors (Farber, 1983). The burnout process may be viewed as a "…general erosion of the spirit" that "impacts precisely those individuals who had once been among the most idealistic and enthusiastic" (Pines, Aronson, & Kafry, 1981, p. 3-4).

Burnout is characterized as consisting of three distinct components (Maslach, 1982). The first component of burnout is *emotional exhaustion*, characterized by depleted emotional resources and feeling exhausted by one's work. The second component is *depersonalization*. Depersonalization results in a detachment from co-workers, clients, and the organization, and may be employed as a coping strategy. The third and final component is *reduced personal accomplishment*, which involves negative self-evaluations. Communication researchers Miller, Stiff and Ellis (1988), however, argue that the unique dynamics of human service work calls for a model of burnout that further considers the unique dynamics of human service workers. People who chose human service work do so because they feel a high degree of empathy for others, thus empathy variables are the best predictors of burnout.

The Empathic Model of Communication (EMC) examines employee-client communication and describes how communication and empathy can act as precursors to burnout. According to this model, interactions with distressed clients elicit empathic processes in workers that influence their perceived ability to respond appropriately, and hence, affects feelings of burnout. Researchers distinguish between two types of empathy (Miller *et al*., 1988). *Emotional contagion* refers to the taking-on, or sharing of the emotion of another person, while *empathic concern* refers to concern for the other's well being without the sharing of emotion (Omdahl & O'Donnell, 1999). It would be interesting to know how it is that hospice caregivers actually *experience* empathy or empathic concern in caregiving.

Stress and Burnout in Hospice and Palliative Care

With the endlessly growing need for qualified healthcare workers, research continues into the effects of stress on the well being of workers. Stress and burnout in the healthcare setting has potential implications for both the physical and psychological health of the worker, patient, and organization (Ablett & Jones, 2007). Yet past research has revealed a great many contradictions as to whether hospice workers are burned out or not. And these contradictions continue to exist, which suggests we still have room for further understanding of these issues.

In the early years of the hospice movement—1970's and 1980's—everything about hospice was uncharted territory. Issues pertaining to role conflict and role ambiguity arose frequently as a source of stress for workers because roles were not well defined. Workers frequently found the boundaries between professional and friends were blurred with clients, and friction existed between referring physicians and the staff who were intimately involved in the day-to-day lives of their clients and wanted to be included in decision making and planning

(Vachon, 1999). Research during this time indicated that hospice and palliative care workers reported substantial levels of work related stress. For instance, two early studies found that staff in one palliative care unit experienced stress levels that were nearly twice as high as those of nurses in other disciplines, and comparable to the stress experienced by newly widowed women and women recently diagnosed with breast cancer (Lyall, Rogers & Vachon *et al.*, 1976; Lyall, Vachon & Rogers, 1980). Yet, even during these years of ambiguity in the hospice movement, hospice workers' stress did not translate into burnout—one of the largest studies conducted in the early years of the hospice movement found the burnout rate in hospice workers was quite low (Mor & Laliberte, 1984).

Disagreement continues to exist as to whether hospice work is more stressful than any other healthcare work. It has been argued that hospice work is particularly stressful because it involves having to constantly cope with death and dying (Gray-Toft & Anderson,1986-1987; Munley, 1985). Yet, there is conflicting evidence as to whether there is a positive association between experienced stressors and burnout in hospice workers—Mallett *et al.* (1991) found that there was a relationship, while Masterson-Allen, Mor, Laliberte and Monteiro (1985) did not. Likewise, Payne (2000) found that despite the difficult nature of hospice work, levels of burnout in hospice nurses were generally low due to a number of mediating factors that make hospice a desirable and supportive place to work.

What we do know, however, is that while the particular stressors that lead some workers to experience burnout vary across individuals and organizations, researchers believe that emotional demands play a factor for caregivers. Just like the *meaning* of death and dying, the values and institutions of the culture shape our responses to it. In other words, emotional demands can be understood by examining the processes by which they are created, understood, and expressed in social interaction with others (Hochschild, 1979). Through socialization, individuals become aware of the rules and norms that dictate the extent and duration of feelings, and the appropriateness or inappropriateness for displaying those feelings in specific contexts (Greer, 2002). In many instances, the regulation of emotion requires tremendous effort—one of the many reasons why research on the role of emotions in the workplace has greatly expanded over the past twenty-five years, and why they are part of this dissertation.

Emotional Labor

Emotional exhaustion is the most widely cited component of burnout (Tracy, 2009). Furthermore, although there is disagreement as to whether hospice work is any more or less emotionally charged than other human service work, it nonetheless has long been distinguished as an industry requiring extensive amounts of emotion work (Mallett, Price, Jurs & Slenker, 1991; Munley, 1985). As stated in the previous chapter, Arlie Hochschild (1979, 1983) was the first to introduce the concept of emotional labor. Primarily based on her research of flight attendants, she described emotional labor as “the management of feelings to create a publicly observable facial and body display” (Hochschild, 1983, p. 7), which is sold for a wage. Hochschild drew heavily from the dramaturgical perspective, which states that the workplace serves as a stage where employees are actors performing for customers. Thus, employees’ performances involve managing impressions, including emotions, in order to achieve desired organizational ends. Employees/actors can manage their emotions through either surface acting—modifying and controlling emotional expression—or deep acting—consciously managing feelings, rather than simply manipulating the expression of emotion in order to express the desired emotion (Hochschild, 1983).

According to Hochschild (1983) both surface acting and deep acting require effort (though to different degrees). For instance, even when a caregiver’s actual feelings match organizationally appropriate feelings, emotional labor is still necessary in order to insure that the emotion is displayed appropriately (Morris & Fledman, 1996). In other words, the caregiver may feel badly for a patient, which is appropriate, while it is inappropriate for the caregiver to cry. It is also possible that the discomfort experienced by some individuals who engage in emotional labor may be associated with having to act out an identity that is non-preferred or low status (Tracy, 2005). While a firefighter, doctor or police officer—occupations that are greatly valued and admired within society—may not experience a great deal of dissonance for displaying detached calmness in the face of a crisis, the same may not be true for a nurses aide who must empty a bedpan without a look of disgust on his or her face. Much of caregiving is considered ‘dirty work’, or work that is generally stigmatized and devalued within society (Hughes, 1984). Add to this stigma, organizational discourses of and about hospice and our cultural diss-ease with death and dying, and the emotional labor performed by hospice workers may be even more difficult than that performed by other human service workers. In any case, researchers have generally agreed that continued, long-term experiences of emotional labor can be linked to negative outcomes such as stress, burnout, reduced commitment, absenteeism, and turnover (Hochschild, 1983; Miller *et al*, 1988: Miller *et al*, 1995; Omdahl & O'Donnell, 1999). However, this issue comes into question when re-casting and investigating emotion through a positive organizational studies lens—something to which I turn to in the following section.

Employees were classified as having high emotion labor jobs if (1) the job involved voice or facial contact with the public, (2) the employee was expected to induce an emotional state in another person, and (3) the employer exerts some control over the employees' emotional activities (Hochschild, 1983). In other words, *jobs* were categorized as either having or not having emotional labor requirements, of which healthcare work was included as having emotion requirements. This construct, however, assumes that all jobs within a category have the same emotional demands and ignores individual and organizational variables that may influence the degree of emotional labor experienced. For instance, Tracy & Tracy (1998) found that 911 call-takers—a job that entails significant emotional stress—did not find the job to be "that stressful," likely due to communicative practices that enabled them to manage the stress successfully, and Wharton (1993) showed that contrary to Hochschild's propositions, performance of emotional labor did not have uniformly negative effects for employees. Likewise, it may be in the case of hospice workers that the emotional component of the job is not a source of stress, or that there are other factors that offset the experience of emotional stress and burnout.

Although emotional labor is most frequently considered a detriment to employee well-being and leads to negative *organizational* outcomes, such as diminished employee commitment or turnover, some scholars contest that notion and argue that emotional labor is not always negative. Emotional labor is best understood as behavioral, according to Ashforth and Humphry (1993), who define it as “the act of displaying the appropriate emotion” (p. 90). Employees, they argue, may be able to conform to display rules without managing actual feelings. For example, an employee may naturally have feelings consistent with the organization’s display rules, thus requiring no effort to display the appropriate emotion. Therefore, they suggested that in addition to surface acting and deep acting, genuine experience and expression of emotion is another form of emotional labor in that the employee is conforming to organizationally required emotions. In this case then, a hospice worker may very well be experiencing and expressing the emotion that the organization wants them to, and while falling under the rubric of emotional labor, the effects would not be negative for the worker because it is ‘genuine’ emotion.

Whether a hospice worker’s experience and expression of emotion is genuine or not, emotion is important in this study because it is at the core of humanness. Emotions are part of our senses. They can alert us when we are placed in a situation that can be challenging, positively or negatively. Emotions are important because they communicate information (Hochschild, 1983). They let us know how to act and what to do—run when we feel fear, hold a hand when we feel affection. Yet, many of the studies in emotional labor essentially operationalize emotion as something negative and dangerous. And much of the literature on emotion fails to acknowledge personal responsibility and control, or "the active role that members may play in resisting and working around cultural controls on emotion" (Waldron, 1994, p. 394). Therefore, we should not assume that emotional labor necessarily leads to psychological harm (Rafaeli & Sutton, 1987). For example, employees who have internalized the organization's emotion norms will likely not experience much psychological discomfort.

So we might ask, how has the larger body of organizational literature on emotional labor been applied to the nursing and hospice field? The emotional labor involved in hospice nursing has been extensively studied by Nicky James (1988, 1989, 1992; James & Field, 1992). She conceptualizes the type of labor these workers perform as 'care work,' a formula she equates to, care = organization + physical labor + emotional labor. In James' (1992) formula, the organization component is not the same as is utilized by Hochschild. For James, organization is referred to in the managerial sense. In other words, nurses (as well as social workers and CNAs) must organize and manage people and services, as well as the physical and emotional components of the job.

In another study of nurses, Bolton (2000) argues that Hochschild's term 'emotional labor,' while useful, "cannot adequately conceptualize emotion work which is altruistically motivated" (p. 581). Many forms of nursing now consist of practices that emphasize a "close holistic relationship between nurse and patient"

(p. 582), and as such, many nurses, “through their skilled performances of emotion management, obviously derive satisfaction from their ability to make a difference to patient’s well being” (p. 582). The study at hand extends out from this line of research in conceptualizing emotional labor as not all bad—in fact we are finding some good as well. However, before closing out this section on emotional labor and moving on positive organizational studies, there is one more emotional labor study that must be considered, as it provides an important piece of the framework with which I approach this research.

Due to the exponential growth in both theory and method, it has been argued that the literature on emotion in the workplace has become somewhat “unruly” and difficult to categorize (Miller, Considine & Garner, 2007, p. 232). Hence, scholars sought to establish a typology that would reflect the ways in which current researchers approach the study of emotion and communication in the workplace—in other words, not so much the way it is defined, but the terrain with which it takes place upon. The first typology proposed is *emotional labor*, which involves situations where emotion is in some way defined and controlled by the organization, and viewed as inauthentic. The second typology is *emotional work*. Emotional work, unlike emotional labor, is emotion that is an outgrowth of work-related communication. Both emotional work and emotional labor involve direct client interaction (e.g. patient, client), but can be distinguished from one another in terms of their control by the organization and authenticity. The third category is *emotion with work*, which involves the emotion that arises from interactions with co-workers in the workplace. Fourth, is *emotion at work*.

Emotion at work considers emotion brought into the workplace, but which did not emanate there, such as worries brought from home or experiencing grief due to the loss of a pet. Lastly, *emotion toward work* exists in situations in which the job is the target of the emotion. Research that looks at various aspects of job satisfaction fall within this typology (Miller *et al*., 2007).

While Miller *et al* (2007) acknowledge that the categories are not mutually exclusive, and an individual could easily experience multiple types of workplace emotion in the same job, it does provide an interesting way to think about hospice work and approach hospice research. Namely, it is important to tease out the different shades of emotion in the hospice setting, as all of it cannot be considered emotional labor. For instance, one hospice social worker recently told me, "Hospice workers are self selected. If you don't have the stomach or heart for this work, you won't last long." What this comment suggests, is that we may need to rethink hospice as purely emotional labor. It may be that the concept of *emotional work* and *emotion toward work* are more applicable. As of now, however, there is little (or no) research that has focused on these issues. In this study, I will be approaching the field with a framework that seeks to understand the contours of emotion in the hospice workplace. That is, I will not focus on the consequences of emotional labor, but examine the themes of emotion that arise in and through communication with others.

Summary of Negative Processes

Regardless of whether or not the dynamics of hospice work have changed substantially over the past thirty years, or whether hospice employees find the work to be emotionally charged and stressful, we do know unequivocally that hospice workers continue to report very high job satisfaction rates. One study found that among 26 nursing specialties, hospice nurses reported the highest job satisfaction rate—98% (Brenner, 1997). The nurses reported the least fulfilling aspects of their jobs were income, opportunity for advancement and work schedules, while the most fulfilling aspects were patient and family contact, autonomy and independence, and the supportive interdisciplinary work team. In fact, contact with dying patients and their families are often reported to be the greatest source of job satisfaction for palliative care workers (Grunfeld, Zitzelsberger, Coristine, Whelan, Aspelund & Evans, 2005). Likewise, in studies of hospice interdisciplinary teams (nurses, social workers, aides, and spiritual advisors), researchers found that team members were very satisfied with their jobs (Monroe & DeLoach, 2004), with nurses reporting the most satisfaction, and social workers reporting the least satisfaction among the group (Monroe & DeLoach, 2004).

So, this past research provides a somewhat muddled picture of hospice workers burnout and stress. On the one hand, we know that hospice work has high empathic and emotional demands that could be quite stressful, while on the other hand hospice workers report low overall levels of stress and burnout. Several reasons may account for these contradictory findings. One reason may be that the interdisciplinary nature of hospice work protects workers from burnout. Unlike nearly all other types of healthcare work, the hospice ideology of teamwork and shared responsibility may free individuals from experiencing the stress and burnout that punctuates much of the literature on human service workers. Another reason for the seeming contradiction may be because of a reliance on self-report quantitative studies that don't actually get at the complex stories or meaning making that would help us make sense of the contradictions. And finally, the existing literature may be contradictory because the preponderance of research has focused on the negative shades of emotion, such as burnout, stress and emotional labor, rather than also examining the possibility for more positive shades of emotion such as compassion, energy or resilience. The next section traces the shift in organizational studies from negative to positive, which provides an important alternative way to think about and approach research on emotion in the workplace.

Positive Scholarship and Organizational Communication

A recent development in the study of organizations and organizational life has been a shift in focus from what is 'wrong,' to what is 'right.' Scholars from a number of academic areas have proposed that for too long, theory and research has concerned itself only with that which is negative and pathological—in both individuals and organizations. Researchers from the fields of psychology and business have primarily led the charge into this burgeoning area of study. This dissertation, however, makes a contribution to positive scholarship from the communication discipline. In this section, I will review the various strains of positive scholarship and theorize positive organizational communication as it applies to this study.

The Call to Positivity

Barbara Fredrickson (1998) challenged psychologists to consider the benefits of studying positive emotions. She argued that psychologists have typically favored negative emotions in theory building, and in doing so they have inadvertently marginalized the emotions that make people feel good. Fredrickson suggested that the reasons positive emotions had been overlooked by scholars were because, 1) positive emotions are fewer in number than negative emotions, 2) as a field, psychology gravitates towards problems in order to solve them and positive emotions pose very few problems, and 3) emotion theorists have focused on explaining emotions in general. While any or all of these reasons could as well be reasons why organizational communication scholars have focused on the negative effects of emotional labor, Fredrickson's second reason—wanting to solve problems—surely is a factor. Many individuals enter academia because they want to be of service to their discipline, and identifying and solving problems is one key method of accomplishing this. But by focusing solely on the negative we miss gaining a more holistic understanding of the situation. This study addresses the positive-negative divide by considering how each may be present in the narratives of hospice workers.

Spearheading the *positive psychology* movement, Seligman and Csikszentmihalyi (2000) argued that studying people in general is more than just trying to fix what is wrong with them, it is "about identifying and nurturing their strongest qualities, what they own and are best at, and helping them find niches in which they can best live out these strengths" (p. 6). Positive psychologists shifted their focus of study away from a focus on weakness to strengths, from vulnerability to resilience, and from pathology to wellness and prosperity. The levels of analysis in positive psychology are summarized as, 1) the subjective level—subjective experience and well being, 2) the micro, individual level—positive traits such as love, courage, spirituality and wisdom, and 3) the macro group and institutional level—positive civic virtues and institutions that foster positive action(Seligman and Csikszentmihalyi, 2000). In short, positive psychology studies "the strengths and virtues that enable individuals and communities to thrive" (Bakker & Schaufeli, 2008, p. 148).

Positive emotions should not be overlooked because they are central to human nature and contribute richly to the quality of people's lives. Therefore, particularly in times of uncertainty, positive psychologists argue that researchers should examine the ways in which positive emotions might be tapped to promote individual and collective well-being. A number of studies have shown that positive emotions broaden attention, thinking, and action, as well as build physical, intellectual, and social resources (Isen, 2000). Through a qualitative approach that allows us to get at the finely nuanced shades of emotion that may not be outwardly visible, this study may very well demonstrate the same in hospice workers. Armed with a better understanding of whether hospice workers experience positive emotions and whether those positive emotions translate into a sense of empowerment and/or well-being for workers, hospice administrators may be able to enact workplace programs or procedures that facilitate both positive emotions and hence, positive organizational outcomes.

Appreciative Inquiry (AI) is an organizational change process emanating but contrasting from the organizational development field, a “deficit based” field of study in which practitioners would begin with the question, “what is wrong and how can it be fixed?” (Bushe, 2007). Scholars from the development field assume that the first step is to identify a problem and then provide an intervention to fix the problem. Following Gergen (1997) and Weick (1984), Cooperrider and Sekerka (2003) cite the dangers of deficit thinking in that it limits the way we frame and make sense of the world, and hence, limits our capacity to conceptualize the possibilities for change. And yet, because it is so widely accepted, we seldom challenge or question deficit-based inquiry. As was evidenced in my review of negative organizational processes, we can see how the perpetual motion of deficit-based thinking has continued in organizational and healthcare research. The study at hand, however, does challenge entrenched notions of ‘lack’ and ‘need’ and expands the frame with which we view research possibilities.

Appreciative Inquiry is an alternative way to think about change. Cooperrider and Sekerka (2003) call Appreciative Inquiry

> A process of search and discovery designed to value, prize, and honor. It assumes that organizations are networks of relatedness and that these networks are “alive.” The objective of Appreciative Inquiry is to touch the “positive core” of organizational life (p. 226).

The first step in AI is to develop an “appreciative mindset” (Bushe, 2007, p. 3), which will allow us to envision and think about new options for action. Since humans evolve in the directions of the questions that they are asked, AI operates from the premise "that asking positive questions draws out the human spirit in organizations" (Cooperrider & Sekerka, 2003, p. 227). In hospice, where the organization generally emphasizes the importance of communication with clients, highlighting the *workers'* stories of compassion will begin to uncover the positive aspects of hospice work and help us envision new possibilities for thinking about the workplace.

Positive Organizational Scholarship

Perhaps the largest and most developed strain of the positive scholarships is that which comes under the label of Positive Organizational Scholarship (POS). Researchers at the University of Michigan have established a Center for Positive Organizational Scholarship (www.bus.umich.edu/Positive/) dedicated to promoting the POS movement in organizational studies and challenging the traditional belief that good management equates with maintaining order and seeking conformity. Although housed in the school of business, the center promotes a cross-disciplinary approach to the study of positive organizational dynamics—one of the reasons why this body of research is of particular importance to this dissertation.

POS researchers do not accuse traditional organizational studies of focusing solely on the negative or undesirable states, but of paying substantially less attention to the positive states, dynamics and outcomes in organizations. Likewise, POS does not ignore the presence of the negative, difficult, or contrary aspects of organizations. It is concerned with understanding the integration of positive and negative conditions, not merely with an absence of the negative. Several reasons have been suggested as to why there has been relative neglect of positive phenomena in organizations: 1) the lack of valid and reliable devices for measurement, 2) the association of positivity with uncritical science, and 3) the fact that negative events make a greater impact on people's lives than do the positive ones (Cameron and Caza, 2004). Therefore, it is important to start thinking about ways in which we can address these issues and subsequently begin incorporating more of the positive aspects of organizational life to organizational studies. By incorporating a range of narratives, including those of compassion, this study extends the existing body of organizational literature as a means to consider how positive events and emotions impact people's lives.

POS scholars readily acknowledge that they are not value neutral either. While the "positive" in POS represents an affirmative bias and orientation, it is not a substitution for more traditional organizational phenomena. It promotes both types of phenomena in relation to one another, but with an emphasis on the affirmative in organizations:

> POS does not represent a single theory, but it focuses on dynamics that are typically described by words such as *excellence, thriving, flourishing*, *abundance*, *resilience*, or *virtuousness*. POS represents an expanded perspective that includes instrumental concerns but puts an increased emphasis on ideas of "goodness" and positive human potential. It encompasses attention to *the enablers* (e.g., processes, capabilities, structures, methods), *the motivations* (e.g., unselfishness, altruism,

> contribution without regard to self), and *the outcomes or effects* (e.g., vitality, meaningfulness, exhilaration, high-quality relationships) associated with positive phenomena (Cameron, Dutton & Quinn, 2003, p.4).

As noted, positive organizational scholarship does not ignore the negative and neither does this study simply shift from negative to positive. Instead, through narrative analysis, I consider and incorporate the ways in which hospice workers experience emotion, whether positively, negatively, both, or neither.

The focus of POS is on positive deviance, which “realizes the highest potential of organizations and their members” (Cameron & Caza, 2004, p. 732). And in some circumstances, those potentials may be realized in situations often overlooked by traditional scholarship. For example, relative normalcy may be exceptional in conditions where deterioration or weakness is expected, or when an organization thrives under circumstances that should make it fail. In fact, some of the most dramatic examples of flourishing in organizations are found in the most difficult and challenging situations (Cameron & Caza, 2004; Cameron *et al*., 2003; Dutton, 2003; Frost, Dutton, Worline & Wilson, 2000). And an example of this may be found in the contradiction between the stress and burnout literature and hospice worker’s report of overall job satisfaction. Researchers may have assumed that the challenging nature of hospice work should lead to employee distress, when in fact there were clear examples of thriving. This dissertation will help to shed light on some of these contradictions by acknowledging that individuals and organizations are never solely one or the other.

It is important to note, however, that positive scholarship has not been without critique. And perhaps the best critique is Fineman's (2006) recent contribution to the conversation in the *Academy of Management Review*. Fineman is concerned with the seductive discourse that presents a "broad vision of the sunnier side of life, where positiveness can be harnessed for noble individual and organizational ends" (p. 270). Although Fineman does not discount the value of positivity, he articulates five problems with the way positive scholarship is currently being promoted and operationalized in the literature. First, he argues that positive scholarship has a moral agenda with humanistic roots and a promotion of social scientific methods. Second, Fineman argues, positivity evolved out of a "moral malaise" and discontent for advanced consumerist society and the belief that the promotion of the positive will somehow counteract the negative effects of organizational life. Third, he states, that the separation of positive feelings for special attention overlooks the adaptive strengths of both positive and negative emotions. Fourth, he claims that positive studies have a distinct mono-cultural lens that stresses the goodness and rightness of positiveness. And fifth, POS may suffer from the cooptation of positive discourse by human resource management may ultimately operate as a tool of oppression. Ultimately, Fineman argues that positive scholarship does not need to be discarded, but calls for a reflective, critical practice of positiveness that "calls attention to where positiveness discourses are emanating from and how different perspectives may, or may not, be honored" (p. 283).

Valid concerns are raised by Fineman regarding positive scholarship and his critique is noteworthy. And I believe that I have an obligation to address his concerns. I do not shift the focus of this study to the positive out of a consumerist society moral malaise, but as a means to broaden the circle of legitimation; That is, to expand the possibilities for studying organizational life. My role as researcher is to access and interpret my participant's stories and narratives, whatever they reveal. I worked collaboratively and collectively with my participants to reveal their "feelings about episodes in their organizational life that appear harsh, oppressive, restrictive, or unfair, alongside those that may have been liberating and pleasurable" (Fineman, 2006, p. 284).

Positive Organizational Communication

Few researchers in the field of communication studies have theorized the study of positive emotional communication in organizational contexts—at least it appears that way from an EBSCOhost search with the terms 'positive organizational communication,' which yields zero results. It is important to consider how this dissertation propels the communication discipline in the direction of building a theory of positive organizational communication. Therefore, I offer that the study of positive organizational communication should consider the way positive *communication* operates in organizational contexts.

Positive organizational communication can emanate from within the organization (e.g., management's positive communication with employees, or the compassion studies cited above), or from the outside (e.g., client stories of positive employee acts). The end result of positive communication, or the scholarship that follows, need not be positive organizational outcomes, though there might ultimately be a positive effect. POS scholars have argued that the scholarship generated through positive research should be rigorous, theory driven, follow scientific procedures and utilize precise definitions, otherwise it risks being nothing more than a self-help prescription for happiness (Bernstein, 2003). Therefore, the end result of positive organizational communication scholarship should be a better understanding of positive communication in organizations and organizational contexts.

The parameters that I have set out thus far for positive organizational communication and scholarship are quite broad. For the purposes of this study, I narrow to a focus on compassion. Although a fairly new area of theory and research, compassion, like much of the research in organizations and healthcare, originated as a deficit based concept. That is, scholars argued that compassion as experienced, displayed, or managed in organizational contexts, had negative consequences for individuals and organizations. Recently, however, compassion has taken a theoretical turn. In the following section, I trace the compassion construct and discuss how it applies to the existing literature, as well as this dissertation.

Compassion and Work

In this section, I review the literature on compassion as it has originated in nursing and social work. More specifically, I explicate two fairly new additions to the concept of compassion in caregiving that are especially relevant to the study of hospice workers: compassion fatigue and compassion satisfaction. Like emotional labor, compassion fatigue is often cited as a stressor that contributes to burnout. In that sense, it can be viewed as yet another negative organizational process. However, the counterbalancing concept of compassion satisfaction provides a fitting segue into the next section where I present my research questions.

While there is any number of definitions for compassion, most people assume that it is a quality that individuals who work in caregiving possess. Like empathy, compassion involves “other-oriented” feelings (Batson, 1994, p.606), however, compassion goes “beyond an individual feeling of empathy and is expressed through action of some sort” (Frost *et al*, 2002, p. 27). Compassion requires “feeling and acting with deep empathy and sorrow for those who suffer” (Stamm, 2002, p. 107). The feeling and expression of compassion carries with it potential problems—as well as rewards. One of the potential problems that arises from compassion is fatigue.

Compassion Fatigue

Compassion fatigue evolved out of the field of traumatology—the psychosocial study of people who have experienced extreme events—and has made its way into the literature on caregiving. Joinson first used the term compassion fatigue in a nursing journal in 1992. Compassion fatigue, she argued, manifests physically and emotionally much the same way as any work related stress. However, there is a difference between the burnout that can affect workers in any setting, and the burnout that affects people in caregiving professions, such as nurses. Three issues were cited that contribute to caregivers’ susceptibility to compassion fatigue: 1) although caregivers perform concrete functions, the essential product they deliver is themselves, 2) human need is infinite and caregivers tend to give infinitely, and 3) caregivers fill multiple roles, for example shifting from administrative tasks to crisis care and back again, and this frequent shifting of roles depletes the caregivers energy.

Sociologist Charles Figley (1995) is credited with fully developing the concept of compassion fatigue, and refers to it as the cost of caring. The Compassion Fatigue Self-test was developed in 1995, and in 1996, Figley and Stamm expanded the measure to include compassion satisfaction. The Compassion Satisfaction and Fatigue Test recognizes that individuals in helping professions are often motivated by the satisfaction they derive from helping others. The Professional Quality of Life Scale (ProQOL) was developed in 1997 to assess burnout, compassion fatigue and compassion satisfaction (Stamm, 1997-2005). All three measures are in wide use today by numerous quantitative researchers who work in a number of social scientific disciplines. And although compassion fatigue rarely, if ever, has been the primary focus in communication literature, it is in some ways related to the concept of the emotional contagion in the Empathic Model of Communication (Miller *et al*., 1988), in which individuals go beyond feelings of empathy to taking on the feelings of others.

Several other terms appear in the trauma literature that are closely related to compassion fatigue—secondary victimization, vicarious traumatization, and secondary traumatic stress. Secondary victimization is experienced among members of a traumatized family system—the primary victim is the person directly involved in the catastrophic event, while other family members are secondarily victimized (Figley, 1995). Vicarious traumatization refers to the development of traumatic symptomology in individuals who work directly with victims/survivors of trauma, and involves “a transformation in the therapist’s (or other trauma worker’s) inner experience resulting from empathic engagement with clients’ trauma material” (Pearlman & Saakvite, 1995, p. 151). Like secondary victimization, vicarious traumatization has almost exclusively been applied to social workers and psychologists, and not across other occupational groups that work with traumatized people, such as hospice nurses and CNAs. Yet, these workers are also directly involved with traumatized individuals—patients and families. It would be interesting to know how secondary trauma might be associated in the current study by asking hospice workers about their empathic engagement with clients.

Secondary traumatic stress, however, is what has become commonly known as compassion fatigue. Compassion fatigue is referred to as a more “user-friendly term for secondary traumatic stress disorder, which is nearly identical to PTSD, except that it applies to those emotionally affected by the trauma of another (usually a client or family member)” (Figley, 2002, p. 3). At its core, compassion fatigue is thought of as an emotional state of discomfort resulting from concern for an individual experiencing traumatic events, and has been compared to second-hand smoke—no one is immune to secondary traumatic stress, but some individuals are more susceptible to its effects than others (Figley, 1995). This would suggest, for instance, that in the case of hospice, some workers might experience compassion fatigue, while others—even those performing the very same job—may not.

Recent scholarly studies have addressed compassion fatigue in a vast array of occupational groups, from child protection workers (Conrad & Kellar-Guenther, 2006) and genetic counselors (Benoit & Leroy, 2007) to HIV/AIDS workers (Smith, 2007), and relating to a variety of trauma experiences, such as survivors of terrorists attacks (Cohen, 2006) and Hurricane Katrina survivors (Campbell, 2007). And although hospice work resides within the parameters of traumatology, and hospice workers work closely with individuals experiencing tremendous physical and/or emotional pain, there is substantially less scholarly literature addressing compassion fatigue specifically in the hospice setting. One recent study sought to determine the relationship between demographic variables (age, gender, marital status), nursing characteristics (shift work, nurse to patient ratios) and compassion fatigue risk (Abendroth & Flannery, 2006). The study revealed that while nearly 80% of the nurses surveyed were in the moderate-to-high risk category for compassion fatigue, it appeared that the demographic or work related variables did not put the nurses at greater risk, a finding contradicted in a previous study. The researchers admitted that a strictly quantitative study such as theirs would not be able to explain the coping strategies or other factors that might help explain their contradictory findings.

Likewise, a study of hospice workers—nurses, social workers, and chaplains—to find out if music therapy reduced compassion fatigue and increased team building, found that while team building was enhanced, there was no change in the level of compassion fatigue (Hilliard 2006). It was suggested that future studies should develop hospice specific measures in order to better understand why hospice workers seem to defy much of the literature on compassion fatigue. If one of the questions is, why isn’t hospice workers’ compassion fatigue affected by demographic and occupational variables, and why doesn’t their compassion fatigue lead to burnout, as the literature on other occupational groups seems to suggest, the answer may lie in the next area of literature to be reviewed—compassion satisfaction.

Compassion Satisfaction

Compassion satisfaction is not the antithesis of compassion fatigue, and likewise, we cannot assume that experiencing one means the absence of the other. There seems to be a balance between the two (Stamm, 2002). Many caregivers believe they experience compassion fatigue, but they may nonetheless enjoy their work because of the positive benefits they derive from it. Their belief system may lead them to feel as if what they are doing is the right thing, and is in some ways is redemptive. However, if compassion fatigue and burnout are combined, a caregiver may lack the energy to sustain any vision of a world in which she or he could find satisfaction. In Stamm’s (2002) conception of compassion satisfaction, efficacy is primary. She states, “Compassion satisfaction (CS) may be the portrayal of efficacy: Indeed, CS may be happiness with what one can do to make the world in which one lives a reflection of what one thinks it should be” (p. 113). And of course, because there have been no studies addressing the experience of compassion fatigue and compassion satisfaction in hospice workers, we currently don’t know if efficacy is in any way a contributing factor to their sense of well-being.

However, if part of trauma workers’ motivation to engage in the work they do is the satisfaction they derive from helping others, then compassion satisfaction is a vital part of the human service equation. Not all trauma workers will experience compassion fatigue (Stamm, 1998). Simply being exposed to traumatic stressors is not a guarantee that an individual will develop psychological difficulties—some must have a protective mechanism that helps them maintain a sense of well-being. In trying to determine what those protective mechanisms might be, Stamm and Pearce (1995) first suggested that caregivers were most at risk of developing negative reactions (such as compassion fatigue) to their patient’s difficulties when their competency and control were threatened. Others contend that the factors that protect individuals (from developing compassion fatigue) are hardiness—defined as control, commitment and change as challenge—and good social support (King, King, Fairbank, Keane & Adams, 1998). However, neither of these explains what compassion satisfaction is and how it may contribute to a workers sense of well-being and fulfillment.

While there have been a few early studies providing support for the positive effects of care work, research has not generally addressed it directly or independently. For example, even though compassion satisfaction was added to the compassion fatigue self-test to measure the positive effects of caring, it is nonetheless measured in concert with the negative. In order to flesh out the satisfaction construct and more thoroughly understand how it connects to job fulfillment and engagement, it makes sense to ask workers to tell stories of compassion. Through the stories workers tell, we will be able to identify not only the overall common themes of compassion, but also the subtler and more finely nuanced mechanisms that may protect them from fatigue and keep them engaged—something nearly impossible to get at when using traditional quantitative measures, as nearly every existing study does. This dissertation will focus a long overdue qualitative lens on the study of compassion in hospice work.

Research Focus and Questions

Although there has been long standing "interest in compassion as a moral imperative" (Frost *et al*, 2006, p. 845) in the healthcare literature, scholars argue that the value of studying compassion in organizations is that "it brings the organic, the moving and heartfelt, the emotional, and the relational elements of life into sharp relief" (Frost *et al.*, 2006, p. 844). Kanov and colleagues (2004) suggest that compassion is similar to empathy, but goes one step further. These scholars developed a model of compassion in organizational contexts by identifying three interrelated processes: noticing, feeling, and responding. First, compassion involves *noticing* another's emotional state. Second, it involves *feeling* for the other's pain and consists of empathic concern, but goes beyond empathy to involve a response to another suffering. The third process then, *responding*, indicates an attempt to alleviate another's suffering.

Communication scholar Katherine Miller (2007) further extended Kanov and colleagues model of compassion and argued that the individuals she interviewed were more likely to describe the second sub-process in terms of *connecting with* individuals, as opposed to simply *feeling for* them. In this way, compassion can clearly be seen as a communicative act and a social process whereby noticing, feeling/connecting, and responding to another's suffering is part of the organizational culture and shared by organizational members. That is, each of these processes must be legitimated and coordinated within the organization—which is clearly evident within hospice ideology and culture.

To date, however, organizational studies have primarily focused on compassion between coworkers (see Frost *et al*, 2000 and Lilius *et al*, 2008 for examples) rather than between service workers and their clients. Yet, two notable exceptions do exist: utilizing Kanov *et al's* compassion framework, O'Donohoe and Turley (2006) explored the ways in which workers in the obituary department of a newspaper responded to grieving clients, and Miller (2007), interviewed human service workers from a number of occupational fields in order to understand how compassion is experienced and enacted by workers through communication with their clients. Both of these studies provide excellent examples of how compassion has begun to make its way into the broader organizational discourses of emotion in the workplace. Neither, however, addresses compassion in hospice workers, as this study does.

Research Questions

Based on the preceding review of the literature on both negative and positive organizational processes, and further building upon the concept of compassion as the three-pronged process of noticing, feeling/connecting and responding, my research questions are:

RQ 1: What are the compassion processes of *noticing* that hospice workers describe in regard to their jobs? What are the barriers to noticing that workers describe in regard to their jobs?

RQ 2: What are the compassion processes of *feeling/connecting* that hospice workers describe in regard to their jobs? What are the barriers to feeling/connecting that workers describe in regard to their jobs?

RQ 3: What are the compassion processes of *responding* that hospice workers describe in regard to their jobs? What are the barriers to responding that workers describe in regard to their jobs?

Summary

In this chapter, I reviewed and summarized the literature that led me to pose my research questions. After further fleshing out the theoretical and methodological frame for this study—compassion and narrative—I formally presented my research questions. In the next chapter, I review my methods of data collection and analysis.

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[1] One of the ways in which hospice was 'sold' to Medicare – and Congress – was as a cost savings plan, and studies confirm that hospice does reduce Medicare costs for terminally ill patients (Taylor et al., 2007). Part of the Medicare Hospice Benefit plan requires that in order for a hospice to retain its Medicare certification, it has to receive 5% of its staff hours from volunteer labor and be able to document the cost savings of using those volunteers. I was surprised to learn that at one hospice where I volunteered, the volunteer's hourly wages were calculated at $19.00 per hour. When I asked the volunteer coordinator how much the CNAs were paid, she grimaced and said, "about $9.00 and hour." When I asked her how they came up with $19.00 for volunteers – because I assure you, the work I do cannot compare in any way to the backbreaking work CNAs perform – she replied that they assumed most volunteers were "like you, a professional whose time is valuable."

Chapter 4

SURVEY OF RESEARCH METHODS

> There is much that goes on in organizations that is extraordinary. It surpasses what we imagine is possible or “normal,” and for that reason, we may discount it as “not representative,” rare, fleeting, or therefore inappropriate for study. Furthermore, our problem-centered approach to studying organizations…may blind us to the everyday acts of extraordinariness in organizational systems. However, if we turn toward instances, processes, structures, and their interaction that produce human flourishing, vitality, capability, resilience, and other positively deviant behaviors, we get new angles on organizational life and a new injection of inspiration to sustain and invigorate our own scholarship (Dutton, 2003, p. 7).

This quote reflects the lens with which I approached this research. Through qualitative methods, I was able to explore hospice workers lived experiences of compassion. These accounts of compassion were but one way in which this study focused on human flourishing and vitality in organizational life.

As was evidenced in the literature review in chapter three, much of the research that frames this dissertation is quantitative in nature and emanates largely from sociology and psychology. Tracy (2009) argues that we need much more qualitative research to flesh out research related to burnout in organizations. In particular, she challenges organizational communication scholars to think outside the

> box and arrow diagrams that linearly connect individual causes, organizational factors, buffering variables and consequences [of burnout]. We need to know the types of interactions, feelings and communication that *construct* the boxes. We need to have thick descriptions of those little arrows. In other words, we need to better understand what happens *in between* the boxes (emphasis in the original, p. 24).

By utilizing qualitative methods in order to elucidate narratives of compassion from hospice workers, this study directly addresses Tracy's (2009) call. In this chapter, I first provide an overview of the methodological rationale, then move on to a description of the research sites, the methods of data collection, and the process of data analysis.

General Methodological Rationale

As Geertz (1973) tells us, the complex and richly nuanced nature of the human experience can best be honored through a method that searches for *meaning* rather than *laws.* While this study was approached from a grounded theory perspective (Glaser & Strauss, 1967), the very nature of qualitative research is iterative and as such, this project called for an emergent design. In my fieldwork I entered the public and private worlds of people who were in the process of dying as well as those who were helping them through the process. An inquiry such as this could not be "given in advance; it must emerge, develop, unfold" (Lincoln & Guba, 1985, p.225). Therefore, using an emergent design allowed me to respond to the phenomena I studied and make methodological choices along the way. I was able to reflect upon, redefine and refocus my research lens as my study progressed.

Additionally, qualitative methods are in keeping with a social constructionist perspective, which suggests that the way we come to experience and make sense of social life is through our cultural understanding of particular social situations and linguistic practices (Tracy, 2000; Waldron, 1994). Through socialization, individuals become aware of the rules and norms that dictate the extent and duration of feelings, and the appropriateness or inappropriateness for displaying those feelings, in specific contexts (Greer, 2002). As Miles and Huberman (1994) state, “A main task [of qualitative research] is to explicate the ways people in particular settings come to understand, account for, take action, and otherwise manage their day-to-day situations” (p. 7). Even when the task is to explicate ‘positively deviant’ narratives of compassion then, workers are describing a key moment of social life. Thus, employing a methodology that enables multiple layers of analysis and thick description provides the greatest opportunity to unveil the “pockets of ambiguity” (Lindlof & Taylor, 2002, p. 6) that exist within an individual’s social reality.

In order to flesh out the richness embedded in workers’ experiences of compassion, I utilized a method of inquiry that involved an interpretive, naturalistic approach to the world. In explaining naturalistic inquiry, Denzin and Lincoln (2005) state, “This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them (p. 3). My desire to understand the experiences of compassion in hospice workers could not be considered in isolation from the ambiguities inherent in the embodied experiences of my participants. Therefore, qualitative approaches grounded in ethnographic participant observation and narrative accounts allow us to see "images through participants' eyes, finding hidden poetry in their voices, and sensing the texture of their lives" (Charmaz, 2002, p. 320).

Ethnography is an *embodied practice*, "an intensely sensuous way of knowing" (Conquergood, 1991, p.180). Through the practice of participant-observation, we privilege the body as the site of knowing. But as richly rewarding and understandably desirable as participant observation can be, as a way of knowing it inherently evokes questions of reflexivity. Eastland (1993) tells us that it is important to ask, "Where do I leave off, and where do my data begin?" or, "How much of my data is me and how much of me is my data?" (p. 135). As social scientists and researchers, we are taught to bracket out our "selves" in the research process. Yet, as Ellis and Bochner (2000) convincingly argue, "As communicating humans studying humans communicating, we are inside what we are studying. The reflexive qualities of human communication should not be bracketed 'in the name of science.' They should be accommodated and integrated into research and its products" (p. 743).

Subjectivity

A distinguishing feature of qualitative research is the acknowledgment of the researcher's culpability in the research process and an appreciation for "emotion, intuition, personal experience, embodiment, and spirituality" (Ellis &

Bochner, 2000, p. 747). That is, the researcher is not a mere recorder of information, but an always potent participant in the ongoing research process. Through the practice of participant-observation, we privilege the body as the site of knowing. As richly rewarding and understandably desirable as participant observation can be as a way of knowing, it inherently evokes questions of reflexivity. We have an obligation as researchers to interrogate our “selves” as we presume to represent the narratives of those whom we study. For knowledge to be meaningful, it must include three sources of information: “knowledge of and about self, knowledge of and about others, and knowledge of and about the context in which meaning can be attributed to the experience” (Goodall, 1990, p. 266). Therefore, recognition of my position, participation and perspective are especially important to articulate now, because, as is clearly evident, my interest in death, dying and hospice, long pre-date the initiation of this dissertation.

In 2002, when I conducted my first ethnographic study within a hospice agency, I was very aware of how much my personal experiences had ultimately influenced my research. Likewise, my subjectivity was no less a factor in this research and dissertation. During the times in which I was engaging in volunteer work, stroking the hand of someone who was only hours from death, I would sometimes find myself feeling like the helpless daughter I had been ten years previously, powerless to ‘make things better.’ When a family member would ask me to change an I.V. or explain the process of intubation to them (neither of which I could even remotely do!), I felt important and proud, the same way I imagined hospice workers must feel each and every day. And yet, when I was sitting and talking quietly with the workers, I nevertheless felt like the outsider—the researcher. In recognizing all these subject positions, and the ongoing personal nature of my interest in death, dying and hospice studies, I argue that this project was not hindered, but enhanced, by my past and present experiences. Because of these experiences and subject positions, I was not only able to better understand the holistic nature of hospice work, but also better understand and engage the literature of emotion and compassion.

Research Sites

This study includes data collected from two research sites: Desert Hospice and Sun Canyon Hospice.[1] Between 2002 and 2008, I have been involved with these two hospices as a researcher and volunteer. Following the description of these sites, I have provided a table (4.1) summarizing their defining characteristics.

Desert Hospice

Desert Hospice (DH) is the second largest hospice in the desert southwest metropolitan area. It is a for-profit hospice owned by a hospice conglomerate that operates hospices in five states. Although the majority of DH's clients are served in their homes, the company operates seven inpatient units throughout the area. Besides one week spent shadowing home care hospice workers as they made their rounds to patients' homes, it was at two of the organizations inpatient units that I conducted the majority of my research. In 2002, I engaged in participant observation at the organization's St. Matthews's Medical Center Inpatient Unit. In December 2006 I completed volunteer training with the organization and engaged in participant observation over the next six months at the Avenida Sur Inpatient Unit.

Both units specialize in respite care—which allows for one-week inpatient stays in order to provide the primary caregiver with respite—as well as pain management and symptom control, and imminent death care. Thus, the patient stays typically averaged one week or less. The units are staffed according to patient occupancy and need. Therefore, a nurse scheduled at one geographical unit, could end up working his or her shift at another unit. The nurses and aids work twelve-hour shifts—either 6:30 a.m. to 6:30 p.m., or 6:30 p.m. to 6:30 a.m. Both units had a full time social worker who primarily worked nine to five, Monday thru Friday. Each unit had a spiritual care provider assigned to it, and that person usually visited two days a week, though would make more frequent visits as needed and/or requested.

Avenida Sur Inpatient Unit

From December 2006 thru May 2007, I conducted observation while engaging in volunteer activities at the Avenida Sur unit. The unit is a 13-bed facility attached to the Avenida Sur Nursing Home. The nursing home provides meal preparation and laundry services for the unit. Avenida Sur is called the "butterfly unit," a reference to Elizabeth Kübler Ross, who lived and died in the area and loved butterflies—a kind of 'Kübler Ross' trademark. After her death, Kübler Ross' son authorized the unit to be designated as a 'butterfly unit.' At this unit, when death is immanent for a patient, a butterfly is placed outside the patient's door, and when the individual dies, the family is given a "butterfly box" containing the butterfly from the door as well as a few other symbolic mementos. The “butterfly unit” designation is a great source of pride throughout the entire organization due to the fact that so few hospices nationwide are given this designation.

Avenida Sur was almost always filled to capacity—partially due to its proximity to the nursing home, which allows patients to be moved in and out with ease—and had a waiting list for open beds. Anywhere from two to three nurses and two to three CNAs worked each 12-hour shift. Volunteers would also be called in to help if they anticipated a particularly heavy workload (e.g. new admissions, demanding patients).

St. Matthews Medical Center Inpatient Unit

This dissertation also utilized data gathered through participant observation and semi-structured interviews in 2002 at the St. Matthew’s Inpatient Unit. At that time, I was conducting research on the discursive practices hospice nurses employed to manage their emotions communicatively, and one of the strategies was the sharing of stories. My fieldnotes were replete with rich examples of emotion and compassion, which is a key reason why I decided to use the compassion literature to frame the study.

Due to St. Matthew’s association with and location next to a hospital, it was the highest acuity unit in the organization, receiving the most critically ill patients. Typically, one RN and one aide cared for five patients. The unit held 20 beds, though during my time there, occupancy ranged from five to ten patients. My research took place over a two-month period in the fall season, and the desert southwest sees in influx of retirees in the winter months—it is during the winter months, then, that the unit generally operates to capacity. I visited the unit on various days of the week and times of day and night so as to observe as great a range of possible situations and perspectives.

Sun Canyon Hospice

From November 2007 thru April 2008, I conducted observation while engaging in volunteer activities at Sun Canyon Hospice. Sun Canyon is owned and operated by a large for-profit hospice conglomerate with hospices in 92 locations nationwide. Like Desert Hospice, the majority of the services they provide are in client's homes. Sun Canyon Hospice is not the largest hospice organization in area, but it does operate the largest inpatient unit in the metropolitan area. It is at the inpatient unit, Hill House, that I volunteered and conducted research.

Hill House

Hill House is a 24-bed (all private rooms) facility. It has its own kitchen and laundry, a full time facilities manager and janitor, as well as its own chapel and minister. Workers at Hill House work more traditional eight-hour shifts (three shifts per day), as opposed to the 12-hour shifts that are more common in healthcare. On the day shift, which I generally "worked," there was one intake nurse staffing the front desk, two RN's or LPN's on the floor working directly with patients, and two CNAs. Because there was always a janitor on duty, CNAs performed far fewer housekeeping duties than did the CNAs at Desert Hospice. The beds were almost always full during my visits, although because the unit was undergoing a substantial renovation of its patient rooms, anywhere from two to four rooms at a time were not available to clients.

Table 4.1: Summary of Research Sites

	Unit location/type	# of beds	Room type	Data collection / observation dates
Avenida Sur (Desert Hospice)	Attached to nursing home	13	Private and semi-private	Dec. 2006 – May 2007
St. Matthews (Desert Hospice)	Attached to large urban public hospital	20	Private and semi-private	Sept. 2002 – Nov. 2002
Hill House (Sun Canyon Hospice)	Free standing, self contained	24	All private	Nov. 2007 – April 2008

Data Collection Procedures

In the preceding section I provided a description of my two research sites—Desert Hospice and Sun Canyon Hospice. In this section, I review my data collection methods and procedures. Qualitative research often relies on a combination of methods as a way to provide rich, thick descriptions of cultural experiences and actions. Likewise, data for the present study of compassion comes from two primary sources: participant observation and semi-structured interviews. Table’s 4.2 and 4.3, listed below, provide a summary of data gathered, and a description of the participants. Following these tables, I provide greater detail on my two primary sources of data.

4.2: Summary of Data Gathered

Type of Data	**Hours spent collecting data**		**Single-spaced typed pages**	
	Desert Hospice	**Sun Canyon Hospice**	**Desert Hospice**	**Sun Canyon**
Volunteer Training	8	4	15	2
Shadowing workers—observation	40	4	105	6
Volunteer activities	63	29	95	43
Interviews—semi-structured/transcribed	23	--	184	--
Interviews—informal/ethnographic	7	1	43	4
Employee training—observation	8	--	6	--
Misc. meetings with contacts	3	2	3	2
Subtotal	152	40	451	57
Total	192 total research hours		508 total pages of data	

Table 4.3: Descriptive Statistics of Participants

Total number of participants within scope of research project	96
Extended observation and/or formal interview	67
Brief observation or informal interview	29
Organization	
Desert Hospice	73
Sun Canyon Hospice	23
Type of job	
Nurse (RN, LVN, LPN)	32
Nurses Aid	23
Social Worker	14
Spiritual Care Provider	4
Other (e.g., office staff, maintenance workers, doctors, etc)	23
Gender	
Male	24
Female	71
Ethnicity	
White/Caucasian	65
Hispanic/Latino/a	6
Black/African/African.American	13
Asian/Pacific Islander	12

Participant Observation

Ethnographic projects are dominated by the intense immersion of the researcher into the cultural setting. This dissertation adopts a holistic ideology of ethnography and utilizes participant observation for the ways in which it can shed light on the relevant aspects of my participants' material existence and meaning systems. Lindlof and Taylor (2002) liken participant observation to "*having been there"* (p. 133). Albeit a somewhat oversimplified definition, researchers using participant observation attempt to empathically understand the culture of which they are studying. And while Wolcott (1995) argues that such an endeavor will inevitably fail because outsiders can never become insiders, it is, nonetheless, the best tool available for fully understanding the significance of context (Wright & Flemons, 2002).

In my first research project at Desert Hospice in 2002, I was primarily an observer. During my visits to the St. Matthews Inpatient Unit, I regularly sat at the nurse's station jotting notes of my observations. I attended one new hire orientation and twice I attended IDT (interdisciplinary team) meetings in which members of the various teams—nurses, social workers, spiritual advisors, and physicians—met to discuss patients and/or procedures. Likewise, at these meetings I was strictly an observer and took notes. During my two months at the unit, I engaged in approximately 25 hours of observation, which yielded roughly 40 pages of transcribed fieldnotes. My fieldnotes focused primarily on the communicative interactions of the nurses and the discursive practices the nurses employed to manage their emotions communicatively. I engaged in informal ethnographic and formal transcribed interviews as well, which I will discuss in greater detail in the next section.

In 2006, my engagement at Desert Hospice turned to full immersion. I underwent eight hours of volunteer training at the organization's main office. After completing my training, I went to "work" at Avenda Sur as a volunteer. During that six-month period, I volunteered at the unit anywhere from one to two days a week, for two to eight hours at a time. I performed a variety of duties including the following: work with the CNAs, engaging in direct patient care, such as feeding and grooming; housekeeping such as changing beds; or family and/or patient comfort care, such as companionship or healing touch massage (a light massage of the legs and feet, and/or arms and hands, which requires no licensing or certification). I also spent a good amount of time just sitting and talking with the workers in the "family room"—the room that was the central gathering place for patients, families, and employees. Total hours of immersion at the unit during the six-month period were approximately 90. While engaged in my various activities at the unit, I took headnotes and scratchnotes (Lindlof & Taylor, 2002), and then transcribed them upon leaving the field and arriving at my home office, usually within 24 to 48 hours. My fieldnotes focused on the communicative interactions between individuals: workers and patients, co-workers, myself and other workers, as well as myself and the patients. Following, is a fieldnote excerpt of just one interaction that I observed while at the unit:

> Elizabeth is 92 and an itty-bitty little woman with a full head of wiry grey hair and dementia. Elizabeth likes to sit in the recliner and that big ol' chair nearly swallows her up. Elizabeth has her own fleece blanket that she covers up with in the chair – she is always cold, which doesn't surprise me given how tiny she is. Elizabeth is Charlene's favorite patient. Every chance she gets she goes in and gives Elizabeth a kiss on the cheek and fusses with her blanket. Elizabeth had been bedridden – or chair ridden I should say – the last time I was here. But today when I go into her room, I find Charlene holding Elizabeth's hands and slowly and

> methodically guiding her from the bathroom back to her recliner. Charlene patiently encourages her, “Now the other foot. You’re doing great Elizabeth! The doctor would be so proud of you.” With each small step Elizabeth lets out an equally small sigh. I smile and think that she must be thinking, ‘why do I have to do this? I’m 92 – carry me.’ She finally makes it back to the chair and gives a little moan when she sits down. Charlene grabs the hairbrush out of the bedside table and starts brushing Elizabeth’s hair. With more concern and attention than any beautician I’ve ever known, she produces a scrunchie and secures Elizabeth’s hair into a neat and tidy bun on the top of her head. Elizabeth, who always looks and sounds as if she is half asleep, turns her face towards Charlene, furrows her brow, tilts her head to one side, and asks, “What do I call you?” Charlene laughs and says, “Charlene. You call me Charlene.’ She throws her arms around Elizabeth and says, “I love you soooo much! ” Then gives her one last peck on the cheek, tucks her blanket in around her and bounds from the room.

I routinely witnessed expressions of compassion such as this at the unit—as well as engaging in such acts myself when I was there.

Likewise, at Sun Canyon Hospice, I was a full participant observer. Because I had undergone volunteer training at Desert Hospice, I was only required to have my training documents faxed to the volunteer coordinator, and then watch 4 hours of videos on health and safety, which I could do from home. While at the unit, I worked directly with the patients and/or families, engaging in conversation or healing touch massage. Whenever possible, I spent time in the employee lounge talking to the staff. The employee lounge was not only the place where the staff took breaks, but it was where the nurses completed their substantial paperwork. I estimate that during any particular visit I spent approximately one-quarter of the time interacting solely with employees, while the other three-quarters of the time involved patients as well. While at the unit, I took headnotes and scratchnotes (Lindlof & Taylor, 2002), and then transcribed them within 24 to 48 hours of leaving the field and arriving at my home office. In particular, my notes focused on the workers interactions with patients and the stories that they told about their work and their clients. I volunteered at Hill House one day a week for approximately two hours at a time. During this time I logged approximately 40 hours of participant observation, yielding 50 pages of transcribed fieldnotes.

Because the majority of my research had been conducted at inpatient units, I wanted to spend time in the field with some home care workers as a point of comparison. Therefore, in June 2008, when I went back to Desert Hospice with the primary purpose of conducting focused interviews, I spent four days in the field, making rounds with four home care workers—two social workers, one nurse and one spiritual care advisor—as they visited clients in their homes. One of the social workers' client territories was a rural community approximately 40 miles beyond the metropolitan city limits. On that day, due to both the driving distance and a once monthly grief support group she led in the community which added to her schedule on that day, I spent a full eight hours with her in the field.

The other three days, I spent half days with the workers—approximately four hours each. Although they warmly welcomed me and seemed genuinely interested in my research, I did not want to be a burden on them and thus chose to spend only a limited number of hours with each of them. In each case, during the time we spent in the car traveling from house to house, I had the opportunity to ask more focused questions.

Although I did not ask every worker I interviewed or observed whether or not they had worked both in the field and in an inpatient unit, of those that I did ask, approximately 85% had in fact performed hospice work in both settings at one time or another in their careers. When I asked workers why they were working in their current position (either in the field or in the unit), or which they preferred, nearly everyone stated either a preference for autonomy, and thus worked or preferred the field, or liked a more traditional work setting, in which case they worked or preferred the inpatient unit. Although everyone acknowledged that the type of relationship you develop with your clients is different depending if you are in the field (longer and more intimate) or in a unit (shorter and more intense), no one cited this as a reason for preferring one work setting to the other.

Interviews

Individuals come to hospice work in a number of ways and for a variety of reasons. Those that I interviewed reported one of three primary reasons: past personal experience with hospice, prior work experience with death, dying or critical care in which they felt disappointed with, or unfulfilled by, the traditional biomedical model of healthcare, or they felt it was “a calling.” And some people, like the social worker below, cited all three reasons for choosing hospice work:

> I’ve been attracted to the field of death and dying from my earliest memories…when I was like ten, everyone made fun of me…I had this dream. I dreamed that I had a job, and my job was to help people turn into driftwood. I would go from person to person and they would turn into these lovely, beautiful grainy graceful pieces of wood…and driftwood floats…it doesn’t sink, it floats! They would lie on the beach, just lie there, and I would touch them and they would turn into beautiful, peaceful, graceful pieces of driftwood and they would float off into the sea, real peaceful like. I just knew that I would end up in hospice someday. And then, when my grandmother died while on hospice, I was positive I would end up here. I just never thought I would end up here as early as I did because I had in my mind that you needed to be very wise to work in hospice. But my interview with Desert was two hours long. They grilled me. They wanted to make sure that I was strong enough emotionally and spiritually. So I think a lot of people are like me and come to hospice with a sense of “been there, done that.” I know what it’s like to work with a hospital team. I know what it’s like to work in a slap-another-bandage-on-it kind of environment, and I know what its like to work in an environment where it is an honor to go to deeper levels and support people. I don’t think the medical field cares about that. When your heart calls…hospice is where you go. (Sarah, SW)

Few people were as visceral or detailed in their response to this particular question as Sarah was. Yet the hospice workers in this study offered rich accounts of their experiences and emotions in dealing with both clients and co-workers. It was evident in the interviews I conducted, that each participant was a “reflective being whose understanding allow[ed] for improvisation and adjustment to various situations instead of merely following prescriptive behaviors” (Hoch et al., 2003, p. 21)

Participant observation is integral to any ethnographic study, however, “there are, of course, no observers of the internal events of thought and feeling except those to whom they occur. Most of the significant events of people’s lives can become known to others only through interview[s]” (Weiss, 1994, p.2). Interviews provide the means with which to “understand the social actor’s experience and perspective” (Lindlof & Taylor, 2002, p. 173); information which can only be gained directly, through the words, utterances, and stories—as well as the silences and expressions of emotion—of those individuals who have cared for the dying. Therefore, in addition to the informal interactions and conversations that occurred during my participant observations with hospice workers and volunteers, caregivers, and terminal clients, I also engaged in formal and informal interviews. According to Kvale (1996):

> In an interview conversation, the researcher listens to what people themselves tell about their lived world, hears them express their views and opinions in their own words, learns about their views on their work situation and family life, their dreams and hopes. The qualitative research

> interview attempts to understand the world from the subjects' points of view, to unfold the meaning of peoples' experiences, to uncover their lived world prior to scientific explanations (p. 1).

This study includes data from seven informal/narrative interviews and 22 semi-structured interviews.

Informal and Narrative Interviews

Informal and narrative interviews are types of interviews which allow the researcher access to the multiple and nuanced layers of human experience. In both types of interviews, attention shifts from a regimented text-centered focus, to the performative and aesthetic dimensions of communication (Langellier, 1989). Furthermore, informal and narrative interviews consider the dynamic relationship between the researcher and the research participants. That is, as an iterative and emergent process, knowledge is gained from the "many turns at talk" (Paget, 1983, p. 78) that continually inform and shape the evolving conversation between the participants. As Corey (1998) notes, narratives swing "between the public and private, between what is said and what is thought, between the individual and society, between the regulations of language and the regulations of the body" (p. 250). In this way, interviewing provides the best way to learn about the unbounded realty of individuals whose bounded reality may be constrained by organizational and cultural discourses of caregiving.

It is important to note the relevance of informal and narrative interviews to this study primarily because of the work I have done. In the capacity of a volunteer, I have been involved in a number of activities that have allowed me access to what has been immensely rich and finely nuanced data. For instance, as a volunteer I have not only performed many of the same tasks as the workers themselves, but I have performed these tasks along side them, and I have shared many cups of coffee and conversations with staff. Although I have tried to keep my research goals in mind at all times, it is impossible (and unethical) to try to limit or bracket out the informal conversations that evolve from these types of experiences and interactions. The least structured of all interview types, the overarching goal of the narrative interview is to find the most comfortable ground for stories to unfold (Lindlof & Taylor, 2002). For example, one of the ethnographic interviews took place over a two-hour period on one particularly uneventful and stormy fall night at St. Matthews while the nurse was on duty. Likewise, the two informal interviews from Sun Canyon Hospice took place in the employee lounge while two nurses were doing their paperwork. And during the four days I spent making rounds with the home care workers, I was able to ask questions of clarification regarding interactions I had just witnesses, as well as some of the questions I planned to ask in respondent interviews while we were in the car traveling between patient homes.

Semi-structured Respondent Interviews

The majority of interview data came from 22 more formal respondent interviews (Lindloft & Taylor, 2002). The purpose of these interviews was to elicit open-ended responses from interview participants. Semi-structured interviews ask the respondent to speak only for him or herself, and it is through these interviews that I sought to access the complex dynamics of hospice work and the experience of compassion. Kvale (1996) describes semi-structured interviews as having a “sequence of themes to be covered, as well as suggested questions” (p. 124), in which the researcher maintains enough flexibility and openness to change the interview course. The researcher must be able to probe and ask follow-up questions to answers given and stories told by participants along the way. Interviews are an “interpersonal situation, a conversation between two partners about a theme of mutual interest…in which knowledge evolves through dialog” (Kvale, 1996, p. 125).

Four of these interviews were from my research at the St. Matthews unit in 2002, two of which were conducted and audio recorded at the agency’s main office in a partitioned off conference room with nurses recruited from a list of six names provided me by the Staff Development Coordinator. All six of the people on the list were contacted, but for various reasons, only two subsequently agreed or were able to meet for the interview. One of the interviews lasted 45 minutes, the other one 75 minutes. Two interviews were conducted via email with nurses recruited through nursing discussion boards.

Seventeen of the interviews were individuals recruited from Desert Hospice in 2008, three of whom I had previously worked with at Avenida Sur. I submitted a one-paragraph summary of my dissertation work to two administrators with the organization—the patient care coordinator for the nursing and nursing assistant staff and the patient care coordinator for the social workers and spiritual care advisors. Each then emailed the summary to their individual employee email list asking that anyone interested in participating in an interview to contact him or her. Each then supplied me with a list of interested employees (the four individuals that I shadowed in the field were recruited from this list as well). When I made contact with the workers, I arranged to meet them at a time and place of their convenience. I met the individuals who worked at an inpatient unit at their respective units and interviewed them there, in an empty room, an office, or family gathering area. For those who worked in the field, I met them either at the main office where they picked up supplies or turned in paperwork, or over the phone when they were at their homes. Interviews lasted anywhere from 32 minutes to 65 minutes. All of these interviews were audiotape recorded. Seven of the interviews I transcribed myself, while ten were professionally transcribed. When I received the professionally transcribed documents, I simultaneously read the document and listened to the audio recording as a first level of data analysis and a check to insure accuracy. Any mistakes noted were corrected at that time.

Finally, one interview was obtained via a nursing assistant discussion board. I was originally concerned that I would not be able to get enough nursing assistants to participate. As noted in the previous chapter, there is very little research on nursing assistants, and I wanted to make sure their voices were well represented in this dissertation. Hence, I posted a thread to the board asking if anyone was interested in participating. One woman contacted me via email, and we conducted the interview via email as well. Once I realized that getting sufficient participation from nursing assistants was not going to be a problem, I did not pursue this avenue any further.

What ended up being a bigger issue of representation were spiritual care providers; I was only able to conduct interviews with three spiritual care providers, and one of those was a nurse who had recently been ordained and was essentially doing ‘double duty’ at an inpatient unit. This low representation, however, is not due to lack of interest, but the fact that there are so few of them. Desert Hospice employs only six spiritual care providers. Therefore, although three seems a numerically poor representation, statistically, it is 50% participation for this organization. While it would have been nice to have more—and I tried, to no avail, to find online discussion boards or websites where clergy would gather—I am satisfied with what I was able to obtain.

During my interviews, I asked the workers to tell me about their work, to share their experiences and feelings about working in hospice, and to recount instances of both routine and more memorable encounters. The questions I asked respondents were meant to elicit stories about, and experiences from, their work-life in hospice—positive and/or negative. For example, most interviewees were asked “Can you tell me about a time when you felt especially appreciated by a patient or client,” as well as “Can you tell me about a time when you felt unappreciated or misunderstood by a client,” and “Is there any one particular incident or patient that stands out in your mind for any reason?” (See Appendix B for the interview guide). Likewise, I asked respondents a follow-up question about similar experiences with the organization or co-workers (“Can you tell me about a time when you felt especially appreciated [unappreciated] by the organization or a co-worker?”) Although not all respondents were asked all the same questions because of time constraints and/or wanting to preserve and encourage the natural flow of conversation, I believe there were ample questions asked of all participants that encouraged them to think about a range of possibilities.

Quality in qualitative research

Utilizing two research sites and two sources of data has a number of benefits that are of added importance to qualitative researchers: rigor and integrity. Numerous researchers and scholars have debated issues of rigor in qualitative research and suggested their own criteria. Two commonly utilized methods for discussing claims or rigor in qualitative research are triangulation and crystallization. Triangulation (Denzin, 2001; Lindlof & Taylor, 2002) involves the comparison of two or more kinds of evidence, such as through multiple sources, multiple methods and/or multiple researchers. Laurel Richardson (2000), on the other hand, counters the idea of triangulation, citing its rigidness and assumptions of fixed points that can be validated. Instead, she offers her notion of ‘crystallization.’ It is the crystal that best serves the postmodern text. Crystals are prisms that refract and allow us to see the myriad of discourses, practices, experiences and realities that interact. She argues that crystallization deconstructs traditional notions of rigor, and states that texts should validate themselves. So, my use of multiple sites, types of data, and types of participants, provide multiple lenses through which to understand issues of compassion at hospice. These multiple lenses, and my ability to compare and contrast multiple types of data, help provide complexity on the issue.

Indeed, many researchers agree that qualitative research is not intended to portray *a single* truth (Richardson, 2000; Riessman, 1990, 1993). Words and actions are context dependant, and constituted through myriad of social discourses as well as power relations. *Relational integrity,* they assert, should be the driving force behind all research relationships. Relational integrity refers to all interactions within the research process—with colleagues, research participants and the data—and maintains that these relationships are sacred:

> That is, we make sure we don't impose ourselves on the person or thing with whom or which we are in relationship (a colleague, an informant, the data, an idea), and, recognizing that what we report in our research is the story of our participation in the project, we also make sure we don't disappear or with draw from these others. We want our informants, our experience, our data, and our analyses to speak for themselves, and we appreciate the degree to which our participation is responsible for giving them a voice (Wright & Flemons, 2001, p.267-267)

Similarly, Ellis (2007) suggests that when conducting research with intimate and/or vulnerable others, we must remain mindful of relational ethics. Relational ethics entails treating others with respect, being mindful of the consequences of our actions on others, and "requires researchers to act from our hearts and minds, to acknowledge our interpersonal bonds to others, and initiate and maintain conversations" (p. 4). My data collection methods are designed to provide opportunities and space for multiple voices, coming from variant points of view, and above all, to respect and honor the stories of all my participants. I now turn to the last component of the research relationship—the data analysis.

Data Analysis

The nature of emergent, qualitative research necessarily calls for an inductive means of data analysis and interpretation. Data analysis, however, does not begin when the researcher leaves the field—it is an ongoing and emergent process as well, and begins moment the researcher enters the field.

In this dissertation, I wanted to reveal hospice workers' experiences of compassion and to make sense of this phenomenon by explaining the recurring patterns of meaning that were revealed in my fieldnotes and through my interviews. The very act of narrating one's experience becomes "an experience of the experience…Understanding is not embedded in the experience as much as it is achieved through an ongoing and continuous experience of the experience" (Ellis & Bochner, 1992, p.98). Yet, narratives are not complete in and of themselves. As an interpretive event, they in turn, require interpretation. They do not "speak for themselves" (Personal Narratives Group, 1989, p. 264). Interpretation, then, is socially situated—the context and participants, including the researcher, shape the intersubjective meaning that arises from the qualitative research process (Denzin & Lincoln, 2005). The process I used to aid in my interpretation of workers stories is grounded theory.

Grounded theory refers to both a method of inquiry and to the product of that inquiry (Charmaz, 2005). It provides for a flexible set of analytic guidelines which enable researchers to "focus their data collection and to build inductive middle-range theories through successive levels of data analysis and conceptual development" (p. 507). The basis of grounded theory methods is its simultaneous data collection and analysis, with each clarifying and informing the other.

Consistent with grounded theory practice, my data analysis began concurrently with data collection. After transcribing my fieldnotes and interviews, I turned to NVivo 7 qualitative software to aid me in organizing my data so that I could more easily reread documents and review what I deemed to be significant pieces of data. Although I used similar categories for analyzing both my fieldnotes, and interview transcripts, I coded them separately, so that I could easily distinguish where the data originated from during analysis and interpretation. Once organized, I read and reread my fieldnotes and transcripts as a means to identify emerging themes of compassion. As patterns and themes emerged, codes were assigned to the observed incidents and statements made. I followed the analysis method described by Lindlof and Taylor (2002) as *open coding*. A creative and inductive act, open coding consists of assigning codes even before knowing what the final categories will be, and asks the researcher to mark data according to "what seems to make cultural or theoretical sense" (p. 216).

As I stressed in the introduction, the concepts of noticing, feeling/connecting and responding were not directly addressed in the interviews—they were among a number of themes that emerged from the data, and which later became the central theoretical categories. Again, appendix B contains the interview protocol that guided my research, and although some workers were directly asked, “What does compassion mean,” “How do you convey compassion,” and “How do you know if someone is suffering,” these were not preconceived or predetermined concepts. I did not approach the study specifically looking for Kanov *et al’s* (2004) framework. However, once data analysis progressed, noticing, feeling/connecting and responding emerged as the studies key concepts. Data analysis and reduction occurred on three levels. At the first level, I was not concerned that my data fit into any particular category—I was primarily interested in synthesizing the vast amounts of data on a micronanalytic level by asking, “what is going on here, what does this mean?” Once transcribed into NVivo, this resulted in approximately 83 first-level codes. By first-level, I mean single words (e.g., “sensemaking,” “caretaking,” and “burnout”) or short phrases (e.g., “confronting one’s own vulnerability, fragility, mortality,” “needing to maintain strong boundaries”) that were meant to capture the meaning of the text. It is through this first-level, unrestricted coding that categories and relationships are further defined (Lindlof & Taylor, 2002).

As analysis progressed, I began to organize the data at a second level by searching for relationships and/or themes in the codes. Second level refers to codes that are more interpretive in nature. And while this reduced the data to approximately 10 second-order concepts, two of these concepts appeared especially large—*suffering* and *emotion*. Under the concept of suffering, I placed such first-level codes as *responses to patients suffering*, *outward expressions of suffering*, *grief as personal suffering*, *inability to control a patients suffering*, and *making sense of suffering*. And in the emotion category, I had such codes as *emotionally intense situations, connecting with patients, dealing with personal grief, and emotional impact of a lot of deaths.* This prompted me to go back and take a closer look at these two concepts and again ask, what's going on here? What I realized was that workers were describing the compassion component of their jobs and the sub-processes of noticing, feeling/connecting and responding to the needs of not only their clients, but themselves as well. From here, I was able to progress to the third level of analysis and fully develop my key categories of noticing, feeling/connecting and responding.

Summary

In this chapter, I provided an overview of the qualitative research methods that guided this research project. I first discussed the general methodological rationale that frames this study. Next, I identified my research sites—two hospices in the desert southwest: Desert Hospice and Sun Canyon Hospice. In the following section I discussed my data collection procedures. In the final section of this chapter, I articulated methods of data analysis. The following chapters will consist of my research findings (chapters four, five and six), followed by my conclusion and recommendations (chapter seven).

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[1] Names of the individual hospices and the workers are pseudonyms here and throughout the dissertation.

Chapter 5

FROM NOTICING TO RECOGNIZING

Preview of Findings

By far, the most widely cited and most important quality my respondents said that hospice workers should possess was compassion. Regardless of whether their ‘compassion’ response was the result of thoughtful introspection (for some it seemed that way), or part of a rapid-fire litany of job qualifications (for others this seemed to be the case), it was clear the longer we spoke that hospice workers experience compassion in many complex ways. Likewise, however, there are times they *do not* experience the compassion they believe their clients deserve. Far from being merely the absence of an emotion (compassion), workers seem acutely aware of when and why they are not experiencing the emotion they believe to be perhaps the most important component of their job. In this chapter and the following two chapters, I examine the themes of compassion that emerged in my research with hospice workers. These themes, which my scholarly predecessors coined noticing, feeling/connecting, and responding, I reconceptualize as recognizing, relating, and responding. Each chapter will conclude with a discussion of the tensions and barriers that complicate and/or impede workers experiences and expressions of compassion related to each individual theme.

Before I begin, it is important to discuss four issues I encountered interpreting my interview data. First, in the Kanov model of organizational compassion that involves the three related sub-processes of noticing, feeling and responding, the aspect of recognizing "suffering" is a key part of the process—noticing suffering, feeling/connecting with another's suffering, and then responding to their suffering. Most of the hospice workers I have interviewed and/or worked with, however, don't view compassion as something you provide to only those who are suffering; rather, my data suggests that participants view compassion as a gift you give and the honor you bestow upon someone who is dying. Just because someone is dying (or has a loved one who is dying), doesn't mean they are suffering. One social worker summarized the differences between how we *culturally* think about death and dying, and how hospice workers think about it, in this way

> We get hooked into thinking, "this is so sad." That is all we can see, "Isn't this sad," or, "this is so unfair, blah, blah, blah"…whatever the story. But if you stand back and see that every person learns and grows through this experience…buying into the pity drama can really complicate things for the person who's making the journey. If I'm like all about seeing you as this poor little suffering thing…well, I'm really going to interfere with your capacity to learn what you need to learn during this very special time. So I just try to keep a mindfulness about it. As long as I don't try to change it somehow or complicate it somehow or impose my ideas about your process…then I can just be a vehicle for love.

So, in the eyes of most hospice workers, their clients all deserve compassion; those who are suffering—physically or emotionally—just deserve a bit little more. Katherine Miller (2007) expanded the notion of suffering to include people who are “in trouble and in need of a compassionate response” (p. 231). And while this explanation still implies that someone should be “in trouble,” I don’t think most hospice workers would balk at such an assessment of their clients’ physical and/or emotional state. Therefore, while my conceptualization of compassion does *not* require suffering as a necessary prerequisite to compassion, at times I have chosen to use the term “suffering” because it is the term most widely used by other scholars.

Second, when my participants were recounting and narrating their individual experiences in hospice, there were times in which it was difficult to practically separate the processes of noticing (recognizing), feeling/connecting (relating), and responding—the categories are clearly not mutually exclusive and far more complex than Kanov *et al’s* seminal description and definition. For example, Susan, a CNA told me about a time that she was changing a non-responsive[1] patient’s gown, and being a particularly slow day in the unit, she decided to massage his feet afterwards just to ‘kill some time’

> So, I’m like just standing there massaging his feet, and I don’t know what I was thinking about, but all of a sudden I felt his legs go limp, like completely relax. His breathing slowed down and got much quieter. I mean, I could see him just really relaxing while I was doing it. It made me feel like I was really making a difference for someone, no matter how small the gesture. I knew that I was really important at that moment. It made me feel really good. And it made me realize that sometimes you can’t just do what you normally do. Sometimes you have to try something

> different, do something you haven't done before because you just don't know what might work for someone and make their last days better.

Kanov and associates theorization of the compassion process is distinctly linear—first comes noticing, which they refer to as "a critical first step" (p. 812), then feeling, and finally responding. But as this excerpt shows, the communicative action (responding) came first, then the noticing and feeling. It appears that the initial action evolved not so much out of her desire to alleviate another's suffering, but out of the boredom of routine, daily activities. And what she took away from this experience was that the action/response might be the most important first step, from which processes of recognizing and relating *may* follow (an idea that I will explore shortly).

Third, although the excerpts above are short, they are nonetheless complete holistic stories of lived experience, and the process of interpreting data from lived experience is fraught with tension. While I utilized an embodied holistic approach when analyzing the data and narratives, I was keenly aware that I was the custodian of the emotionally laden individual experiences of workers, and I was making interpretations based on a set of criteria devised by academic scholars. And as with most (if not all) qualitative research, the interpretations I have made, may not be the same interpretations another researcher would have made. The interpretive process is, however, an important endeavor in order to advance organizational communication discourse on compassion. Furthermore, although the components of compassion may occasionally resemble puzzle pieces (or a circle) rather than a linear process, I have ordered my findings according to the criteria advanced by Kanov *et al*, and utilized by O'Donohoe and Turley (2006) and Miller (2007): noticing (which I reconceptualize and rename *recognizing* in the next section), feeling/connecting (which I will later reconceputalize and rename *relating*) and responding.

And finally, while the overwhelming majority of my data constitutes the ways in which hospice workers experience compassion in their jobs, the workers identification and articulation of various tensions and barriers to the compassion process were frequent and significant enough to warrant their recognition and discussion in this dissertation. Although this data is less plentiful, I feel that my participants would want this data acknowledged as a part of the hospice work experience.

As previously noted, hospice workers are keenly aware of instances when they are unable to experience compassion, the emotion or job skill/quality that they believe to be vitally important. Therefore, it makes sense that if workers feel compassion is the first and foremost characteristic of their job, then the inability to feel or display compassion also evokes strong feelings in them. At times, I found that worker's would describe actual instances in which they recognized that compassion was absent, or when there was a barrier that threatened their ability to experience some aspect of the compassion process. At other times, however, they discussed aspects or issues of the job that they did not specifically identify as a barrier to compassion. It should not be assumed that they are mutually exclusive. In other words, what *may* be a barrier to recognizing for one worker *could* be a barrier to responding for another. As will become evident shortly, no aspect of the compassion process is rigid or rule governed, but clearly slippery and subjective. The interpretations I have made are based on current scholarly research and the interpretive, ethnographic methods of analysis discussed in chapter three. I will now move on discuss my findings on recognizing in the compassion process.

Processes of Recognizing

The first of the three interrelated elements of compassion highlighted in Kanov *et al'*s model is that of *noticing*. These scholars state that noticing, "requires an openness and receptivity to what is going on in those around us, paying attention to others' emotions, and reading subtle cues in our daily interactions with them" (p. 812). Furthermore, they assert, noticing can be the result of cognitive processes whereby someone consciously recognizes another's suffering, or can manifest as an unconscious emotional reaction to that person's suffering. They caution, however, that we are more likely to notice another's suffering if we have been through, or experienced, similar pain or suffering, and may have a more difficult time noticing another's need for compassion if we are preoccupied with other things. Given that Kanov and associates model of compassion is conceptually grounded in organizational behavior (specifically, compassionate behavior between employees) and its link to an organizations overall performance and productivity, this seems like a satisfactory theorization. With regard to hospice workers, however, their theorization falls short. A hospice workers' job requires them to focus on 'the other.' Although a worker can 'do the job' without experiencing compassion or engaging in overtly compassionate communication, compassion serves as a key standard by which hospice workers evaluate themselves as well as their co-workers. In other words, in many ways, compassion *is* the job, not simply an ancillary occurrence in the organization that can be seen or interpreted as detrimental or beneficial to organizational outcomes.

Katherine Miller’s (2007) research, on the other hand, found that among the human service workers she interviewed, the noticing component of compassion entailed “not only the need for compassion, but also noticing details about another’s life so that the compassionate response can be made in the most appropriate manner” (p. 235). For her respondents, noticing was more complex than conceptualized by Kanov, clearly closer to how my participants articulated this sub-process of compassion. I believe the term *recognizing* may more precisely identify this process than *noticing*. Noticing, by definition and theorization, suggests awareness, attention, and observation. Recognizing, however, goes further and implies identification with the target of compassion. In other words, as a component of compassion, recognizing implies that we are able to do more than notice, that we must be able to understand and apply meaning to what we notice—an important aspect of this sub-process for hospice workers. In regard to this project, I found that hospice workers discussed recognizing in two ways: cognitively and intuitively. The difference between these to concepts can be understood in this way: at a level of active engagement and skill is cognition, and intuition is that which is tacit or emergent. I begin with cognitive recognizing.

Cognitive recognizing

At the cognitive level, my respondents alluded to several types of recognizing which I will discuss. Quite clearly, for hospice workers, the process of recognizing on the cognitive level means more than just being ‘open and receptive’ to the needs of their clients, it means actively searching out someone’s need, and is generally facilitated through listening. For example, nurse Irene was explaining how she does not assume that the suffering reported by a patient is in fact what is really bothering them, and states that the most important part of her job is

> Listening, listening, listening. Patients and their families will tell you what they fear, what they worry about, what they believe in, what they value. But you must listen openly and ask questions. Like sometimes, people say they are in pain, but what they really want is someone to sit and talk with them. I say, “tell me about your pain.” Sometimes it is an attention getting device and that means that I have to find out what is really going on with them.

In this example, Irene demonstrates how the process of recognizing entails making extra effort to get at what she believes is the root cause of her patients’ distress. Likewise, a social worker Beth described the job of ‘listening to notice’ in this way, “I have to do more than listen to words—I have to listen to the meaning of words, and then ask questions to clarify.”

Making the extra effort to notice is seen as necessary because of the holistic nature of hospice care—patients are part of a larger social system that includes a medical diagnosis and community of caregivers, as well as an array of unique psychological and spiritual issues that they are likely to bring with them. As social worker Leah stated, when patients come on to service, “We start hospice thinking. I mean, you know, you don't know if the patient just lost two sisters, or a son died very young, or, did the wife just find out she's sick? You have to stop and think about this stuff." Hence, need or suffering almost never looks the same in any two people. As nurse Mary remarked, unlike other types of healthcare nursing, recognizing means, "You have to be able to see a *person,* not just a list of diseases or complaints." And for spiritual care providers, there is often an additional challenge to be confronted. One of the spiritual caregivers I interviewed stated that he is often the last person the patients want to see because when individuals are involved in the 'busy work' of dying, and care is kept at the medical/social level, they may be able to avoid the spiritual and push off the reality of their terminal condition. Yet, other members of the interdisciplinary team frequently call him in to help identify/notice the patient's suffering. David commented:

> Occasionally, the nurse or the social worker…refer the patient to us, saying "She's sad. If you want to talk to her sometime today, that would really help us out. Something's bothering her and she won't talk to us." So I go. Even though, you know, people will never ask for me personally and that can be a significant challenge. But I can always tell when they're not sharing the whole story, or there's some pieces missing. And afterwards, what I'll do is I'll just ask myself, "What am I not hearing here? What am I missing?" Or, I mean, "Is there something you need to tell me, or you don't need to tell me. Is there something you need to tell God or someone in your family? Or do you want to talk to somebody else?" You know, I

> know that when people's eyes water up a little bit, there is something there. And I'll touch right here [*touches his forearm*], and say, "it's okay to be angry, it's okay." And then, a lot of times, the real tears will come.

Through the process of "deep listening" (Stein, 1998, p. 213), or "empathic witnessing" (Kleinman, 1988, p. 10), this spiritual caregiver puts forth extra effort to notice a client's suffering by interrogating both what he hears as well as what he *doesn't* hear. The task is made even more challenging when considering that his initial presence may not be entirely welcome. Yet, he understands that he needs to "pay attention, to listen to what is not being said (or to what is being said but minimized) and [learn] the art of 'waiting' and 'asking the right questions' rather than having the right answers" (Wright, 2006, p. 20).

The recognizing process entails visual observation as well. In describing how they attend to recognizing their client's need, hospice workers report that they have "observed their [clients'] actions and facial expressions" (Hannah), or that they "can see it in their body language" (James). More often, however, hospice workers report that they not only visually observe a client's need, but that it is in their patient's eyes where they see suffering and need. For example, social worker Leah explained to me some of the differences between clients who are younger, verses those who are older

> You know, sometimes with younger people you get a much more juicy kind of energy going because, you know, this isn't fair. To be 87 years of age or to be 37 years of age and dying of breast cancer, you can't help but think this isn't fair on some level. And the 37 year-old, well they're

> gonna have something they want to talk about. They're gonna tell you exactly what's what, and how angry or sad they are. But when people are in their advanced eighties and they've been coping with their illness for a long, long time, and many of their cohorts and family members have died and they've moved into a place where they're like…they give up, you know. They don't have that much to say about it. But all you have to do is look into the eyes and you'll see…you'll see their words, you'll see their thoughts and their pain. They don't need to talk…you just have to look.

In this example, Leah describes a situation in which listening is not the means for assessing a client's need because the client doesn't provide any of the verbal indications that deep listening is being called for. Instead, she relies on a special kind of observation in which she sees/notices through her clients' eyes. As Mary (RN) commented, "I can see it in their eyes. I can't explain it any better that that. Just that I can see it in their eyes."

Likewise, *lack* of eye contact was also cited as an indicator of need. A number of nurses, social workers, and spiritual care providers said that they "knew something was up" when their patient wouldn't make eye contact. Sarah, a social worker, described how she had a client that she felt wasn't "letting me in" so that "I could help her." She said she knew this because her client wouldn't look her in the eye when they talked:

> I think I finally made some comment about … I forget exactly what I said about eye contact. I think I said something like, "I've noticed that when

> we talk your eyes will drift off." Well, she thought about it for a minute and said, "Well, maybe it's because when I look at you I see where I'm going." She said when she looked at me she knew she was dying…because I represent hospice. It was a real breakthrough! I knew we'd reached a new level in our relationship and I could REALLY start to help her now.

As is evidenced in this example, Sarah very much believed that 'the eyes are the mirrors of the soul,' and her client's need was a need of the soul. Without eye contact then, she felt that she would be unable to fully see what her client needed.

What was particularly interesting about Sarah's story was that it came in response to a question in which I asked workers "What is your most memorable experience since working in hospice?" I had originally contacted Sarah through email asking if she would be interested in participating. In the email I included sample questions I would be asking, this question being one of them. When we met, she was bursting with enthusiasm, stating that she couldn't wait to share her answer to this question, and then proceeded to tell me this story. The part that intrigued me the most—at first—was that when her patient looked at her she saw death, and this was a source of pride for her. Upon reflection, I recalled that for hospice workers death is not the worst thing that could happen to someone—everyone will eventually die. Dying with sorrow or an aching soul, however, could be the worst thing to happen to someone. In this respect, Sarah's story demonstrated the importance of recognizing in the compassion process. The ability to notice and interpret the intricacies and nuances of her client's non-verbal behavior enabled Sarah to then connect and respond to her clients need.

Last of the cognitive processes I identified in my respondents was the act of direct questioning. Although direct questioning was the least cited process of cognitive recognizing that my participants mentioned, it is noteworthy nonetheless. Three people mentioned this as a path to recognizing, and only one participant said that she always asks people if they are suffering and how they are suffering. For another, Leah, questioning is an option only when other methods fail:

> I admit, some people I feel it is difficult to tell if they are hurting in any way. My best way of telling is if they are withdrawn and out of touch with things. Sometimes you can tell just by talking to them that they are struggling with something. But then sometimes, if you just can't figure it out, you just have to be very upfront and open in asking them what is wrong.

In this excerpt, Leah talks about the things she looks for first. When those signs are lacking, only then does she resort to asking.

I don't assume that because only three people mentioned direct questing as a method of *recognizing,* it means that my other respondents don't ever engage this strategy. It would seem, however, that direct questioning would be one of the most efficient routes to identifying an individual's need for a compassionate response. Yet, many hospice workers seem hesitant to directly question their clients. There may be a couple of reasons for this. First, several of my participants alluded to bad experiences they have had with clients when their clients felt they had been “pushed too far.” Workers are keenly aware that individuals come to hospice with uniquely individual circumstances, physically and emotionally. While they have physical tasks and obligations they must immediately fulfill for their clients, they do not know exactly where in the emotional process of dying their clients are when they come on to service. Trying to assess their clients’ emotional state is undoubtedly one of the first tasks they must accomplish when confronted with a new patient—get it wrong, and the results can be traumatic for everyone involved. For example Annie, a social worker, told me about an elderly woman who was the primary caregiver for her dying brother. She recounted:

> Her brother was slipping fast, and we needed her to make some decisions. I mean, I don’t want people to be blindsided and have to respond at the time of death to all these little pieces that might not be in place. So even though it didn’t seem like she wanted to talk about it at first, once I started questioning her, well, she really opened up. It seemed to me like she got it and was strategizing options and all…we were having the most heartwarming conversation…I left feeling like, oohhh, this is what hospice is at its very best. Then, she came back a couple of days later and now she was this very much enraged, absolutely enraged, old woman. I mean she complained about me to everybody. She said that I had taken advantage of her and her brother, said I told her things that I didn’t…and I had to just sit there and take it, I had to let her have her feelings. I mean, it was a real eye-opening experience for me. I mean, boy am I careful now!

Hospice workers walk a tenuous tightrope when assessing new clients. As nurse Jane remarked, “death brings out the best and worst in people.” If many (or even one) of a workers experiences are like Annie’s, it makes sense that that they may not want to directly question their patients.

The second reason workers may not directly question their clients is that they may believe they should not have to. In short, hospice workers believe, cognitively or intuitively, that the ability to independently assess a client’s condition is a skill they should possess. As Frank, a nurse remarked, “I’m the expert—the doctors defer to me and the patients and their families look up to me.” While traditional biomedical models of healthcare privilege the objectifying impersonal ‘gaze’ (Foucault, 1973), hospice ideology patently rejects the notion that dying individuals are nothing more than the sum of the (ill) parts they bring with them. Individuals are complex, holistic beings that cannot (and should not) be treated in terms of isolated parts. Thus, it may be that workers view direct questioning as a type of traditional biomedical practice, or they may not believe that their clients can respond on a holistic level because of the suffering they may be experiencing.

Intuitive recognizing

Although my participants most frequently described the process of recognizing as taking place at the cognitive level, recognizing at an intuitive level also arose in their stories. Given the possibility that a hospice patient may be non-responsive, and hence, not emitting the kind of outward physical or psychological signs of distress described in the existing compassion research, stories of intuition were particularly interesting and unique. Workers described in great detail the process of intuitive recognizing, whether their patients were responsive or not. As nurse Janet stated, "I've always been hyper intuned to those who suffer. I just know…I can sense it, even in absence of all things physical and tangible." Another nurse, Dianne, called herself "the whisperer—like the horse whisperer, only with people who are dying." The horse whisperer is a man who has a remarkable intuitive connection to horses and the ability to ease their suffering, so to compare oneself to this person suggests that Dianne sees herself as particularly exceptional and gifted at her job.

And yet another nurse, Charlene, explained how her ability to intuitively notice one patient's need led her to a lifelong career in hospice:

> In 1980, for my last practicum with a home health agency, we were studying hospice because the agency was planning to start one. Well, I had a DNR [do not resuscitate] patient and my head nurse told me to just shut the door and check if he was breathing every 2 hours. This did not feel right and probably started me on my hospice journey as I sat with him until he died.

In fact, workers often alluded to their "sixth sense" as a means to notice suffering. One day when I was volunteering at Avenida Sur, I heard singing coming from one of the rooms and I looked in to see one of the CNAs, Susan, singing hymns at the bedside of a woman who was nonresponsive and very near death. I stepped in and asked Susan if the woman was someone she knew. She said "no," but:

> I've been walking past this room all day, and every time I would look in and she just looked so sad and so lonely, you know. But I just kept on working and every time, every time I felt that she was pulling me, calling me in. Then it hit me… she doesn't want to die alone. I just knew that was why I was being pulled in.

Susan further stated that she intended to stay at the bedside until the woman died, or until friends or family arrived, because she could sense that the woman wanted and needed her to be there.

A number scholars have studied intuition in healthcare in general (see King & Appleton, 1997, for a concise review of this literature) and argued that hospice/palliative care practitioners in particular, engage in more intuitive knowledge due to the holistic and personal nature of work (Dunniece & Slevin, 2002; Kennedy, 1999; Schon, 1996). One time when I arrived at the inpatient unit for a volunteer shift, I ran into Daniel, the unit manager, and Gary, a 61 year-old lung cancer patient, coming out the door to sit on the bench and get some fresh air. I joined them on the bench and we talked for about ten minutes about fishing, Gary's favorite sport. When we all returned to the unit, Daniel and I made our way to the office and Gary retired to his room. I noticed Daniel quietly shaking his head back and forth, so I asked what was bothering him. He said, "Gary. He's really scared." Later that day, I wrote in my fieldnotes:

> I don't know where Daniel got that Gary was scared. I was there. He never said anything about being scared. In fact, to me he looked and talked as cool as a cucumber. Like he thought he'd be out fly-fishing next week.

> And I don’t think Daniel has had an ongoing relationship with this guy. I think he just met him when he was admitted. Could it be that Daniel is just so in tune with the terminally ill that he could intuitively get that Gary was scared from a fishing conversation?

It seems as though Daniel’s intuition, reinforced by years of experience, may have enabled him to recognize Gary’s fear (which I didn’t recognize). In fact, there were numerous times when Daniel would ask me to do something, like sit with a particular nonresponsive patient when no family members were present, because, as Daniel would say “he’s sad and doesn’t want to be alone,” an assessment of the patient and his or her emotional state that I didn’t understand (nor did I question).

Fish and Coles (2005) use the metaphor of an iceberg to describe the nature of healthcare practice and intuition. What lies above the surface is the awareness of experience and practice, the doing. What lies underneath is the sum of the practitioner’s personal experiences, values, beliefs and feelings, all of which ‘buoy up’ the doing, and it is at this level that intuitive knowing resides. Like Daniel’s experience with Gary, it is possible that Susan may have had an intuitive experience with the woman she sat vigil with. It is impossible to know for sure, but what matters most is that Susan believed that was the case. So, while the woman may or may not have been ‘calling her in,’ Susan certainly believed that it was the bottom of the iceberg that led her to notice, and hence believe, that the woman did not want to die alone. I will now move on to discuss the barriers to recognizing that emerged in my interviews and the stories told by my research participants.

Barriers to Recognizing

I found that workers often attributed barriers to recognizing to various organizational factors. They often talked about organizational factors that they felt hindered their ability to fully recognize need in their clients. More specifically, workers identified three organizational factors related to work dynamics they viewed as particularly problematic: caseload, paperwork, and regulatory requirements. All three, in practice, are interrelated. That is, paperwork is based not only on the particular agency's requirements, but Medicare regulations, while the amount of, and ability to complete the required paperwork is dependant on the workers' caseload. Regardless, all three were, either collectively or individually, usually blamed on the organization and/or its administrators, and blamed for the workers' inability to devote the amount of time they felt necessary to recognize their client's need.

Many, if not most or all, of these factors didn't seem, at least to me, to be unnecessary or particularly out the ordinary with regard to the ongoing maintenance of organizational functioning in a hospice agency. However, it also doesn't particularly surprise me that workers regularly brought up these issues. I found that, if given the opportunity and vernacular, hospice workers would clearly self-identify as human service workers, not organizational professionals who should be bound by organizational rules and regulations.

Hospice workers feel that it is the 'hands on,' psychosocial, healthcare work that is most valuable and which defines (or should define) their work identity and job description, period. Hence, organizational functioning emerged as the primary source of barriers to compassion, and in ways that indicate these barriers make them unable to engage in the process of recognizing. For example, nurse Carrie, in response to a question about how she would describe a bad day at work, stated, "My bad days are almost always about something related to the office, like low staffing, unrealistic assignments, pointless meetings, etc., as opposed to something that happens with a patient." Carrie's response clearly illustrates how workers segregate their jobs into two distinct realms—the client and the organization, with the organization blamed as being more problematic.

Social worker Sarah, who worked in the field and whose territory covered a large geographic area, discussed at length her frustrations with caseload, paperwork, and regulations:

> Sometimes I am so rushed with appointments scheduled back-to-back. And I'll have multiple issues that need to be completed and I have to put them on the backburner because they [her supervisors] want me to complete this piece of paper or that. Then I end up having to take my personal time to do all the paperwork. I don't think they realize just how far I drive on a daily basis.

At the time that I was traveling in the field with Sarah and she was telling me this story, the agency she worked for was requiring that the nurses and social workers start using laptops or handheld computers to take and log notes. While such technology might seem standard in this day and age, these computers were met with much resistance. Sarah explained her perspective on the new technology:

> I have to document everything now, and not like I was initially trained, which was to do clinical notes by hand. But now you have to go thought this whole process of click, click, click. I mean, I know its important but it slows everything down and I think in the end, the payoff is minimal. They want us to take these computers in with us to our visits. I just can't do that. They're heavy…it's…to me I see it as an obstacle, it feels invasive. To sit there with my nose in a computer, typing while someone is talking. I just won't do it. Even if it means that I end up working later to do my documentation, well, so be it. When I am with a patient, I want to give 100%, but all this other stuff gets in the way and I don't feel like I have been able to give fully to each and every patient. I just get angry and burn out.

The fact that Sarah only saw the use of the computer as problematic and did not perceive any sort of note taking (e.g., the way she was trained to take clinical 'notes by hand') as intrusive in a relationship, is not all that surprising. Change is often unwelcomed by workers, and Sarah's resistance to the use of the computer was, hopefully, temporary and short-lived. But her story highlights one of the ways in which hospice workers described routine organizational struggles, processes and functions as barriers to recognizing, and hence compassion, to their clients.

Summary of Recognizing

Hospice workers described the process of recognizing their clients suffering in two ways: cognitively and/or intuitively. Table 5.1 summarizes these findings.

Table 5.1: Summary of Recognizing

Theme	Strategy	Behavior
Cognitive	Making extra effort	Being open and receptive to seeing the person, not just the disease
	Deep listening	Listening for both what is said and what is *not* said
	Observation	Through eye contact or lack of eye contact
	Direct Questioning	Being open to asking whet is wrong
Intuitive	A sixth sense	Being "hyper in-tuned" to peoples suffering.
Barriers	Organizational factors	Caseload, paperwork, and regulations create overload and impede ability to identity what clients need

Most frequently described, recognizing at the cognitive level entailed workers making extra effort and actively seeking out clues to their client's needs. Workers stated that this process was best facilitated through listening to both what is said and, perhaps more importantly, what is *not* said. They also cited visual observation/seeing as a means to notice another's need. The eyes as the locus of need pertained to both the workers' ability to see their clients' needs, as well as being able see their clients' needs in their clients' eyes. Lastly, and least frequently cited as a means to notice suffering at the cognitive level, was direct questioning. Although direct questioning would seem to be an expedient way to assess need, only three participants alluded to directly asking their clients how they were suffering. Two possible reasons for this reluctance were offered: prior negative experiences with direct questioning, and/or the belief that they (hospice workers) should have the expert knowledge and skills to assess need without asking.

Participants also described recognizing at the intuitive level. At this level, recognizing was akin to a "sixth sense." Given that many hospice patients are unable and/or unwilling to talk about their condition and needs, workers often pride themselves on being able to intuitively feel what their clients need. With regard to barriers, workers typically identified organizational factors as the things that threatened their ability to recognize their client's need. Specifically, it was caseload, paperwork and regulatory requirements that were the most frequently cited aspects of organizational functioning workers talked about.

In sum, just as workers described the process of recognizing at cognitive and intuitive levels, they also alluded to cognition and intuition in the next process of Kanov *et al* and Millers' (2007) model of organizational compassion—feeling/connecting—that I will move on to discuss and reconceptualize as *relating* in the next chapter.

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[1] In hospice, an individual who is non-responsive is generally close to death, anywhere from a day to a week. They are nonverbal and nonresponsive to their surroundings. Depending on their physical condition, of course, they can (and unfortunately sometimes do) feel pain. Exactly how *unaware* they are, however, is up to much debate. Nearly all hospice workers believe that individuals who are non-responsive have, to varying degrees, the ability to sense others' presence, feel touch, and/or hear peoples voices up to the time of death…sometimes beyond. The unit manager of one inpatient unit I worked at believed that an individual's soul would hang around the room for a little while after he/she died—we had strict orders to leave the lights and music on, as well as the tabletop Zen-like waterfall (for the deceased's enjoyment), until after the morgue came and removed the body (and hence, I guess, their soul as well).

Chapter 6

FROM FEELING/CONNECTING TO RELATING

Kanov *et al* contend that at its core, compassion is about feeling. Because individuals can notice someone's suffering without connecting with the sufferer, just as they can respond to someone's need without ever developing an emotional connection with them, we don't enter the realm of compassion until we actually feel for another's suffering. As noted previously, when Miller (2007) applied Kanov and colleagues model of compassion to her study of human service workers, she argued that her respondents were more likely to describe this sub-process in terms of *connecting with* individuals, as opposed to simply *feeling for* them.

Miller's extension of the Kanov model of compassion is further noteworthy for two reasons. First, when Kanov *et al* conceptualized their model of compassion, they argued that it was processual and consisted of 3 interrelated elements. That is, compassion is the process of recognizing another's need, feeling concern of the other, and then being moved to respond in a way that will ease the others' suffering. Yet, in their articulation of the concept of feeling, they imply that this crucial second element is itself compassion: "People feel compassion for someone else…Moreover, the feeling of compassion implies that the object of one's compassion is experiencing some sort of pain or suffering…Feelings of compassion thus connect one person to another's hurt, anguish, or worry" (p. 813). In other words, their conceptualization curiously suggests that the second element of compassion is feeling compassion. Miller's model seems to clear up Kanov's quagmire by describing the second component of compassion as *connecting* with others, not simply *feeling* compassion for them. Miller's reconceptualization thus replaces the second element of the compassion process, moving from the affective (psychological), to the experiential (relational, and yes, communicative), and also avoids using "feeling compassion" to define compassion.

If forced to choose, I believe Miller's "connecting" better captures compassion than Kanov et al's "feeling." However, my data suggests that it's not necessary to choose between the two. That is, we must not entirely dismiss and replace affect (Kanov's term "feeling") and replace it with Miller's "connecting." With regard to hospice workers, both articulations bear fruit. My respondents were able to describe feelings for their clients that led them to respond to their clients suffering, without indicating that they felt particularly connected to them. This may be because some clients are non-responsive and leads us to question whether the ability (or possibility) to interact is a precondition to feeling *connected*, as opposed to simply *feeling* concern or empathy (either of which, however, can move an individual to respond with a compassionate act). Clearly, with regard to caregiving in general, and to hospice caregiving in particular (in which workers often can only 'imagine' the implications and impact of their care on and for their patients), the knowledge and skills that workers call upon are not solely clinical, but situated in a web of social, cultural and embodied experience as well (Skott & Eriksson, 2005).

An umbrella term that I believe best explains the second component of compassion—and incorporates both feeling and connecting—is *relating*. Akin to identification, *relating* encompasses the possibilities for both feeling and connecting, while not privileging one over the other, or requiring both. Relating is, in fact, defined as identifying with, feeling for, and connecting with, thus it embraces the communicative and embodied nature of caring. Therefore, I will be using the term *relating* in reference to this particular sub-process of compassion, though not to the exclusion of feeling and connecting, which, at times, accurately invoke the embodied experiences of workers.

Further attesting to the interrelated nature of these terms, my respondents described this sub-process in multiple ways, as both cognitive and affective, similar to the way in which Kanov *et al* and Miller viewed this component. At the cognitive level, workers described relating as thoughtful and purpose driven. At the affective level, feelings of empathy, concern, *and/or* connection were described as spiritual or intuitive. For example, social worker Sarah described hospice as "the business of trying to align with people so that your hearts kind of beat as one." Or, as social worker Annie remarked when asked what made her relate more with one person than another:

> I think its just maybe they remind you of someone you loved. Maybe they went through something that made you remember something you went through. Maybe you just spent so much time with the family that you've just grown to love them. Maybe they're just so adorable and cute, that you can't help but wanting to visit them more. Sometimes you just know it and other times you have to work at it.

In similar fashion to the ways in which respondents described the process of *recognizing* on both cognitive and intuitive levels, this brief excerpt illustrates the multiple levels in which workers relate with their clients. Unlike Miller, though, my respondents were equally likely to describe empathic concern for their clients (e.g., “compassion means caring about what your clients are feeling and are going through, and then wanting to help them however you can” [Mary]), as connection with them (e.g., compassion means that “I shift away from myself so that I can accompany them on their journey” [Irene]). As I noted, some individuals *seem* to be able to feel for a client’s suffering and not necessarily describe a connection with them—or at least they report it that way. The unifying thread appears to be workers belief that they are better caregivers when the sub-process of relating is present. I will begin by discussing the process of relating cognitively.

Relating Cognitively

For hospice workers, relating with their clients can be both a source of joy and grief. Nurse Dianne remarked, “it is impossible to do this kind of work and not form bonds, and when there are a cluster of deaths in a short period of time, it can really drain you emotionally.” Yet regardless of the implications, workers frequently talked about actively seeking connections and creating bonds with their clients on a cognitive level. By engaging various thoughtful and calculated strategies, respondents stated that they often were able to establish connections even under extremely hard and/or stressful conditions. For example, by “taking the role of the other” (Meade, 1934, p. 254), one CNA, Faith, described how she is better able to understand her clients’ perspective. She stated, “Sometimes people are just so mean and cranky that I don't even want to be around them. But then I stop and think, I'd be mean and cranky too if I were dying. It helps put everything in perspective."

In much the same way that participants talked about looking and listening as a path to recognizing a clients' need, they described relating as an active process made easier by listening and/or looking for possible connections. For example, social worker James defined compassion as "the ability to let yourself hear and see someone fully so that when you give, you give fully." Likewise, nurse Carrie, who I interviewed at one of the inpatient units, talked about something she does each day to facilitate connections with her patients:

> So when I come to work, I always stop at the front door and say a little prayer. I pray and ask God to please not let me be so busy that my heart does not hear my patients. I need to be able to be sensitive to their needs and completely open and available to help meet those needs.

Carrie's remark implies more than simply wanting to be open to recognizing her clients' needs; She clearly recognizes the importance of relating emotionally with them. It is only through a *heart*-felt connection that she feels she can be the best caregiver to her client. And regardless of whether she actually accomplishes this on a daily basis or not, her remark shows that she purposefully thinks about relating and its part in the compassion process.

Meanwhile, another nurse, Hannah, provided an example of how thinking through a situation led to a connection when she was given a patient that the intake nurse had described as rude and angry:

> Even though I'd been warned that she was rude and angry, she wasn't. During our first meeting, I just stopped and asked myself, "What's going on with her?" Then I figured it out, she's from New York and having an aunt from New York, I was able to see that she was making jokes and when she realized I got it, it opened up the doors so she could talk about her fears and ask the questions she had. And we ended up really connecting and having a wonderful relationship and I still keep in touch with her son to this day! Everyone was happy, my patient, her family and my supervisors.

Much like Carrie's example, Hannah's story goes beyond the process of recognizing to the realization that relating is not an either-you-have-it-or-you-don't proposition. She made an effort to understand her client and then found common ground upon which to build a relationship—something that she initially saw as an important step to meeting her client's needs, but which ended up benefiting her personally and professionally as well.

Another way in which my participants talked about relating was through uncertainty reduction (Berger, 1987). For example, a number of my participants alluded to the importance of *presence* in relating. As social worker Annie remarked, "I need to remain present in mind and behavior. I have to stay tuned in to what they [clients] are thinking and feeling, because if I don't, they will know it in a second and I'll never gain their trust." This respondent's remark is just one example of the role uncertainty reduction plays in healthcare interactions. She suggests that her presence (both physically and psychologically) is necessary for her clients to reduce their uncertainty about her and trust that she has their best interests at heart. Individuals receiving hospice care—patients, family members and friends—often experience significant amounts of anxiety and uncertainty, and among the ways that uncertainty can be reduced, as Annie implies, is through increased verbal and affiliative nonverbal communication.

Uncertainty can also be reduced through self-disclosure, and another social worker discussed how sharing information about herself helps build connections with her clients. In this excerpt, Leah, an inpatient social worker, is telling me about how her clients respond when her husband brings their one-year-old baby in to the unit once a week:

> They love it! They come out with their cameras, "Can we take a picture with your baby?" And it also helps me bond with them on a different level. We don't talk about our personal lives too much because it isn't about us…it is about them. But I think little bits and pieces helps you connect with your patient. I find if we share a little bit about our children, about places we've traveled to, about hobbies, like reading, it helps. So when they see you, they feel a little bit more connected.

Leah went on to talk about the importance of reducing uncertainty in children so that she can establish a relationship with them:

> I find myself sharing a little bit more when I'm trying to connect with children. I find that children who come in here are grieving over a parent or a grandparent and sometimes they're a little bit more guarded. So when I'm around kids I just try to be a little bit more relaxed, and a little less

> formal. I'll be like, "Hey, do you guys want to pop in a movie? Do you want a snack?" Then I'll take them a snack, and I sit and say, "Oh, I heard your grandma or grandpa's here. Do you have any cool stories to share about them? I don't know much about them yet. I'm a social worker, and it'd be kind of neat." And they kind of just, you know, look very guarded, and then I'll say, "Well, you know, I was nine-years old when my grandpa was really sick," I go, "Gosh, that was really hard for me. Do you feel the same way?" And then, you know, I talk a little bit more about my experience, and I find that works really well. They really open up to me, and then they start hugging me, and when I see them, they run up to me.

Leah later summarized these two stories by saying, "Sometimes you have to use different strategies with children and adults, but either way, if you give them enough time and show them you care, they will eventually open up."

Likewise, a number of respondents discussed the importance of patience and time in developing trust and relating with clients. In recounting an experience similar to the one that social worker Sarah recited with regard to her being a visual representation of hospice and terminality (p. 93), social worker Beth recalled this relationship with a client:

> At first she was in denial and was angry at me because of what I represented…you know, hospice, dying and all. But as time passed and I let her take things at her own pace to accept my help, she trusted me enough to be able to talk and cry, and at times laugh. Just before she died she put her arms around me and said, "I love you." It was really amazing;

> I feel like we really connected.

Social worker Annie discussed one of the ways in which she builds a relationship of mutual trust and respect with her clients that grows over time by doing what she called informal life reviews. She said

> For me, it’s really about getting to know about their [clients’] life. I connect with them and they connect with me when I ask them questions about their life. And then each time I meet with them I ask them to tell me a little bit more. We will just sit and talk about hobbies, what jobs they used to hold, where were you born, and so forth. Light and informal. You get a lot more information that way, than if you are walking around with a clipboard. It’s really cool when I can walk down the hall feeling really good, and like, oh my gosh, there is Mr. so-and-so. He used to be a crop duster and he used to have his own plane.

Nurse Dianne further described relating over time in this way

> When you have the same patient for three months, you get really close to them. Probably because you’re with them when they cry, and they’re grieving, and you’re with them through those times, and that makes you close. It joins you at the heart, you know.

In this instance, Dianne implies that a connection is an inevitable outgrowth of time spent together. Yet it is clear that time wasn’t the soul arbiter of the connection. Emotion played a role as well. Frost *et al* (2002) remind us that individuals are emotional beings who “experience connection and belonging through feeling” (p. 26). And like Dianne, many of my participants alluded to one powerful aspect of both hospice work and hospice workers—the authentic experience and expression of emotion.[1] As Marcy, a spiritual care advisor put it

> I think like most of the people who work in hospice, I’ve always been deeply compassionate and concerned with others. It only made sense to dedicate my life to hospice work. I don’t think there is anywhere else that you can laugh and cry with people all in the same breath.

Statements such as this clearly suggest that hospice resides within Miller *et al’s* (2007) organizational typology of ‘emotional work.’

Last of the cognitively based relating strategies that emerged in my data are those that develop through difficult situations and/or difficult clients. Difficult clients/situations *can* operate as a deterrent to relating for some individuals and in some situations as well. But given the nature of human service work and human service workers, I was not surprised to find that many hospice workers not only thrive on these situations, but also cite them as powerful bonding experiences. For example, when I asked social worker Leah if she could identify something in particular that facilitated relating and connecting, she said

> Not really. It just varies you know. Sometimes it's the real difficult patient that we really enjoy to love too, because they have such high needs, that you're constantly working to support them and care for them, that once they do die, we miss them, because you got so used to spending so much time with them.

And in response to the question about a particular patient or situation that is particularly memorable, social worker Brianna told me about a patient she worked with for over a year. In Brianna's words:

> The woman [the patient] and her entire family were a mess! Her mother was a substance abuser, separated but not divorced from the father; her house was being foreclosed upon. The father, who was her caretaker was a drug addict and would disappear for days at a time. She didn't have health insurance; she was non-compliant with her medication. I've never worked so hard for someone, getting her cab passes, getting her to comply with doctors orders…It was totally exhausting, but I've never felt more valued and closer to anyone because of it. When she was dying and I went to her house to see her, her nurse told me that she probably wouldn't recognize me because of brain mets [metastasization]. But when I walked in the room, she did recognize me!

Being recognized by the woman in the end undoubtedly helped seal Brianna's feelings of closeness. But the way her narrative unfolded, indicated that those feelings would have persisted even if she hadn't been recognized (literally and figuratively) for her hard work.

Likewise, nurse Lisa told me about her first hospice patient, a woman of 35 dying of cancer. It so happened that Lisa's father had recently died as well, and when she called the main office after her emotional first visit with the young terminal woman, "sobbing that I couldn't do my job," her supervisor told her that she would have to, as there was no one else to take the woman as a patient. Lisa elaborated:

> I learned many things about hospice work from that patient. I learned that

> it is OK to cry with them, I learned the immense emotional support that they need, and I learned that I can be that support. And nothing feels better than that or brings you closer to your patient than when you work hard to fulfill their needs. I will forever be grateful to my supervisor for not letting me back out of that one. She knew what she was doing.

Lisa's comment about relating through hard work came in response to a question about a "bad day" she experienced in hospice. And it's not hard to see why she would have viewed her first day as a bad day. Yet, in this instance, she was able to contextualize the experience within the larger framework of job training and personal/professional growth. In fact, a number of workers described hard work and/or difficult patients as both a bonding mechanism and an important component of hospice socialization. As one CNA (Summer) recalled, "I may bitch about people who are always complaining or needing attention, but it does keep me on my toes and reminds me why I'm here. And in the end I come to really love those people because of that."

Intuitive Relating

Besides actively seeking relations and creating bonds with clients on a cognitive level, my participants talked about relating in an intuitive way. Here, workers often described relating with individuals on a purely affective level. CNA Peggy chillingly described a time when she was eating lunch in the family room and she was suddenly overcome with the feeling that she needed to go to the bedside of one of her (non-responsive) patients. She said that she felt as if she was being pulled by the man and said, "I knew he needed me, but I felt right then like

I needed him too. So I went, and he died about an hour later.”

As discussed in the last section, when my respondents talked about listening and looking for connections on a cognitive level, they talked about relating as an active, engaged and purposeful process. They indicated that this process, and hence bond, was an important component of their job, i.e., they were better nurses, aides, social workers, and spiritual care providers when they were successful. At the level of intuition, however, they talk more in terms of the visceral evidence that they have made an impact on their client. Although they are proud of these moments, workers don’t suggest that they feel they are better nurses/CNAs/social workers/spiritual care providers for it, but cite these experiences as instances of mutual benefit—for the client and themselves. They describe it as feeling like, or seeing that, they made a difference. A number of individuals stated that they felt “intune” or “most alive” when they could “look in their [patients] eyes and know that I made a difference” and/or “feel like I am valued.”

For example, CNA Faith talked about a time when she was feeding an elderly dementia patient his lunch:

> I would give him a bite, and he would go “ummmmm,” like it was some delicious steak or something. Every bite! I couldn’t help but start laughing after awhile. Then he would laugh because I was laughing. So it was like, “Ummmm. Ha, ha, ha. Ummmm. Ha, ha, ha.” I just thought what a simple thing I’m doing and it is bringing such happiness to both of us.

Similarly, spiritual care provider David recalled a time when he was to officiate at a memorial service. As he was about to leave for the service, a man called saying that his mother was nonresponsive and very close to death from Alzheimer's. The man asked David if he would come over and say a prayer for his mother. Although David didn't feel he had time to make the visit, he also knew that if he were needed, he would have to make the stop:

> So I think, you know, I'll just go and have a quick prayer, and then go to the memorial service. So I get there, and her arm had gone through the bedrail, and sort of like really twisted, and it looked like it was really uncomfortable. So I maneuvered it back and was talking to her son and praying for her, and oh my gosh, she grabbed a hold of my hand TIGHT. I thought, oh my gosh, I've got to get out of here! But it was like she was saying, "Hold on, you're not going anywhere, you're staying here with me." That is what it felt like, you know. So then I told her, I said, "I've got to go, I have a memorial service. I'm going to pray for you, then go to my service, and I promise you I'll be right back." Well, I said the prayer and she relaxed her hand, and I left. That told me, don't you ever assume that Dementia, Alzheimer's, Parkinson's, whatever, people cannot hear you. You just can't go in and do the rote thing and leave, because people feel you and you feel them, they touch you, you touch them.

Besides showing how the sub-process of relating can occur affectively, both Faith and David's narratives further indicate the way in which the compassion process does not necessarily unfold in a linear fashion. Both of them were engaged in acts that most anyone would deem "compassionate." Yet, they didn't relate to, feel for, or connect with, the person until the act had been performed. This is particularly evident in David's situation, as he did not have a prior relationship with the woman or her son, and he was approaching the visit with a sense of hurried anxiousness.

Another way in which hospice workers describe relating is through various forms of identification with and/or to their clients.[2] Nearly every hospice worker I have encountered has talked about a client, or clients, they have had that have reminded them of someone they have known and loved (or hated). These patients can ignite a wide range of feelings in workers. For example, if the patient is someone of similar age, mannerisms, and/or appearance of a worker's spouse or parent, the ensuing caregiving experience can be one of love, joy, trepidation or dread, depending on a litany factors. But regardless the emotion engendered, it is almost always an intuitive response that will either bond them or, perhaps understandably, distance them. Nurse Charlene offered a chilling story of one such experience. Before she began working in hospice, Charlene's daughter had died in a tragic accident at the age of six. A number of years later, after she began her career as a hospice nurse, she was assigned a six-year-old girl as a patient. She was hesitant to take the case, but when she found out that the little girl was actively dying (and hence, she wouldn't be developing a long relationship with the girl and her family), she agreed.[3] Charlene recalled:

> The day I met her, she appeared mesmerized by something around me. When I asked her what she was looking at, she told me there was a very shiny, bright light around my head and that it hurt her eyes. I thought

> maybe she was just photosensitive, so I went and got my sunglasses for her to wear, and she happily put them on. But she kept staring away at me. Then a few hours before she died, she was talking to another little girl…who was unseen by either her parents or me! I asked her who her friend was, what she looked like. She described my six-year-old daughter to a tee, including a birthmark she had been born with. I can't really describe it, but it was like I was overcome with this rush of warmth I hadn't felt in years.

Charlene went on to say that she thought the reason she ultimately agreed to take the case was because her own daughter had pulled her in—she knew that her mommy would be able to give the little dying girl the best possible care in her final hours.

Another nurse, Jane, fought being assigned a patient because the woman reminded her of herself—they were of similar age and backgrounds.[4] In the end, however, she said that it was a rewarding experience because she witnessed the amazing care that the dying woman's husband provided her and her three children from a previous marriage. She told me that it had "renewed [her] faith in humanity." In both these examples the nurse's initial apprehension, because of the identification, was resolved and the interaction ultimately evoked feelings of warmth and satisfaction.

Social worker Annie cited an additional benefit to identification. Sometimes, if a client or situation evokes identification in a worker, he/she will use that identification as a means to help guide their actions. For example, when

Annie was called in to explain to an elderly gentleman, who reminded her of her grandfather, that he was going to be placed in a nursing home, she recalled:

> During the visit, we had an instant connection. I did experience some counter-transference you know, because of my grandpa. But I was able to control it. But as a result of the transference, I knew exactly how to handle and approach the topic with my patient.

It seems experiences of identification function as a form of uncertainty reduction for the hospice worker and contributes to the process of compassionate relating. And in many ways, this finding mirrors Rivera's (2010) research on U.S. Border Patrol Agents and the ways in which they make distinctions between "bad" immigrants (drug dealers, smugglers, etc.) and "economic migrants" in search of the American Dream. Many border agents view the pursuit of the American Dream as laudable, in spite of the fact that the immigrant had broken the law in coming to the United States, or are themselves the children of immigrants. In these situations, identification enables the agents to feel compassion for this group of individuals. For hospice workers, if they meet someone just like mom/dad/grandma/sister, etc., then they feel like they may have an advantage when trying to understand how to deal with and care for the individual.

Annie's excerpt above alludes to one final intuitive component of the compassion sub-process my respondents cited—relating that arises instantly. Individuals often describe this process as "spiritual." Nurse Hannah explained that her "gift" to hospice nursing was that she

> gets it…and them. Not so much by what I say or do, but rather a palpable

> spiritual bond. There is always trust there [between her and her patients] right from the beginning. I've been hearing this from day one from my patients and my co-workers.

And David, the spiritual care provider, described the instantly arising intuitive component of spiritual relating for chaplains in this way:

> A lot of chaplains, whether they're fire department, police, hospice, hospital, whatever, a lot of them have an innate, unique gift that enables them to build a rapport in just a few minutes, and it's about trust. And when you kind of have a feeling of trust that you can nurture with somebody, especially if they're dying, well that's really beautiful.

Although there were only a few references to instant (or nearly instant) intuition, they were nonetheless salient experiences to the individuals that talked about them.

Relating Through Reciprocity and Acts of Appreciation

The final way in which the process of relating manifested in my research was through reciprocity and acts of appreciation—when a client (patient, family, or friend) does or says something that workers see as unexpectedly kindhearted and/or compassionate. Clients frequently come to hospice service in crisis, dealing with extreme physical and emotional stresses. Being able to alleviate some of that crisis for their clients is viewed as an honor or gift that an individual has to give. No worker that I encountered ever expected any acknowledgement or thanks from the patient or family, as they understood that patients and families are overwhelmed and absorbed in their own trauma, which oftentimes extends to long after the individual has died. Therefore, when clients or their family members did something—anything—nice, it meant a great deal to workers. And many times, those acts of appreciation facilitated relating.

For example, I remember a respite care patient, Anna, at the unit where I volunteered that everyone seemed to avoid. Anna was what hospice workers would call “high maintenance” –a client who needs extraordinary amounts of attention, for any reason. Anna’s situation was compounded by the fact that she didn’t speak English. Meanwhile, none of the employees at the unit spoke Spanish, Anna’s native tongue. Anna was tiny and frail, but nonetheless fidgety and constantly moving. Those factors, coupled with her dementia, created a dangerous combination. The week that Anna was staying at the unit, the staff frequently asked me to spend time with her to try and tire her out. That was no easy job and I did not look forward to it. In attempting to attend to this duty, I helped Anna into a wheelchair and walked her up and down the halls of not only the hospice unit, but the halls of the adjoining nursing home, which was quite large. As I pushed, Anna weaved and bobbed in her chair, reaching and grabbing at anything and everything possible. On good days, we stopped by the aviary in the nursing homes waiting room and Anna watched the brightly colored birds for five or ten minutes before she started fidgeting again.

Anna’s sole caretaker was her one and only grown son, Frank. Frank visited daily and always seemed exhausted and overwhelmed. One day after he arrived, he asked me to come into his mother’s room. He handed me a small bag containing four pan dulce—a type of Mexican sweet bread, and a gift just for me.

He told me how he couldn’t thank me enough for working as a volunteer, for being unselfish enough to spend time with his mother. He told me how hard it was being the primary caretaker of someone who is old and needs constant attention. He continued, “Sometimes, I feel so alone. I can’t tell you how comforting it is to know that there are people like you and this place there for me and my mother.” I never dreaded spending time with Anna after that. In fact, I’d rush to her room and she would throw her arms open and squeal, “Mi bebé!” (My baby).

Hochschild (2003) argues that, from an emotional perspective, acts of gratitude and appreciation are seen as extra, “something beyond what we normally expect” (p. 104), and are ‘gifts’ themselves. In my experience with Frank and Anna then, Frank’s unexpected acknowledgement and gift led to my relating to his mother. *His* act of appreciation and gratitude towards me essentially facilitated what amounted to a ‘third party’ connection, a connection between Anna and myself.

Somewhat similarly, nurse Lisa told me about an act of compassion that she witnessed in one of her patients—the compassionate act of a dying man to his family. She recalled:

> This one particular family really stands out in my mind. There was this young father who was dying of cancer and he videotaped himself reading books to his young children and giving them advice. He recorded a tape for each year of their lives so they would have a tape for each year that they got older. That was so powerful and amazing. I still keep in touch with this family 10 years later!

In Lisa’s example, witnessing the compassionate act of the patient towards his family (of caretakers), led to a long term relationships between Lisa and the man’s family. Interestingly, there is some evidence in the bullying research that managers working with aggressive managers may begin modeling the aggressive, bullying behavior (Lutgen-Sandvik, Namie & Namie, 2009). So it seems that witnessing behavior may prove to be a powerful tool for organizational scholars, researchers, managers, and/or trainers—regardless of whether the behavior is positive or negative, it appears that (some) workers will model what they see/experience.

The evidence of relating through acts of appreciation and gratitude were numerous. Even though these acts/gifts were not expected, they were not entirely unusual either. Social worker Leah told about her drawer full of thank you cards from families that she “will never throw away. They are one of the things that make my job worth it.” But cards that come ‘after the fact’ of death have quite a different in impact from those things that happen unexpectedly in the moment. Those are the ones that lead to relating. Nurse Janet recalled one such experience:

> I had a patient that the team wanted to throw a little party for his 97th birthday. But when we arrived, he and his caregiver had made a little party for us. Even though he spoke very little English, he responded to our concern and caring. It was one of the most touching moments of my life and every time I saw him after that, I felt honored to be with him.

And CNA Debra told me about her favorite patient:

> He was a dear, sweet man who was a retired doctor. We called him ‘doc’,

> and even though the saying goes that doctors make bad patients, that was not true for doc. He was a wonderful patient. When I would walk into his room to say hello, he would take my hand and look me in the eye and say, "Hi honey, how are you today?" Through all his pain and agony, he would ask about me! He truly had an amazing bedside manner and he was the patient! I will never forget him.

What clearly attests to the power of these acts is the fact that most of the experiences recounted came in response to a question I asked participants about a particularly memorable patient or experience. In other words, out of the many years of work experience, and thousands of individual encounters, workers overwhelmingly cited reciprocal acts of compassion as not only the most memorable, but made clear that they were an important part of the relating sub-process. There are, however, a number of issues workers experience that can interfere with experiences of relating.

Barriers to Relating

Workers discussed a number of barriers that could potentially impede experiences of relating. For example, workers frequently talked about the need and importance of maintaining boundaries with their clients. Nurse Jane warned, "People are people you know, whether they are dying or not. If you don't put up some firm boundaries, they will take advantage of you." My respondents cautioned that individuals who failed to maintain firm boundaries often suffered from burnout. Social worker Annie told me that she'd seen "dozens" of hospice social workers over the years who had poor boundaries and "that throw themselves into their patients' lives. They completely feed off that feeling of feeling needed. But they'd eventually come to resent it, burn out and leave unhappy. Or worse yet, stay and make everyone else's life miserable." It was this second group of workers—those without boundaries who stayed on the job—that Annie warned often failed to relate and connect with their clients. She continued by saying that this lack of boundaries and continued employment led some social workers to shut down:

> They just give, give, give, without really feeling anything because they think that is what they are supposed to do. They don't really get that what their clients need is a well-balanced social worker—someone who has their personal and professional life all together.

Yet, while boundaries were viewed as necessary in order protect them from burnout and hence, enable them to relate, workers also recognized the danger in maintaining boundaries that were 'too firm.'

For example, nurse Lisa told me the story of how she first came to do hospice work. When she was in nursing school, the students were required to do rotations in the hospital's hospice unit. Unlike her classmates, she really felt drawn to the work, but her supervisor cautioned her, and all the other nursing students, that hospice work would:

> tear us apart if we didn't have firm boundaries. So when I took a job in hospice, I put on this shield of armor to protect myself…from what I don't know, but I kept hearing the words of that supervisor. Even though I had really liked doing the hospice rotations in nursing school, when I had the

> job, I just wasn’t feeling the joy I’d hoped for. Then it dawned on me…drop the armor! I was meant to do this work and that shield was keeping me from connecting with my patients and from feeling that joy and fulfillment that I knew was there somewhere. I realized, it’s a fine balance between nothing and too much. But if you have a good support system at work and home, you can do it.

In Annie and Lisa’s examples above, boundaries had both positive and negative qualities and consequences that either directly or indirectly affected the ability to relate compassionately with their clients. In this way, boundaries—too strong or too weak—may potentially impede relating. Or, as nurse Daniel stated, “You have to have good boundaries but not walls.”

A second barrier that workers alluded to with regard to relating pertained to judgementalness. In fact, the second most commonly cited trait/quality my participants cite as needing for hospice work, following compassion, was the ability to suspend judgment. Workers discussed the need to remain non-judgmental while not compromising their personal values and beliefs. CNA Katie, in response to my question about what compassion meant to her, stated “It means being able to accompany them [patients] on their journey without subjecting them to any judgment, assumption, or influence from my own life.”

As noted previously, workers encounter people from all walks of life and for whom they must care. Experiencing negative feelings toward them can greatly hinder, if not entirely prevent, them from relating. Although workers can experience negative feelings toward clients for any number of reasons, such as their clients' unwillingness to accept their terminal diagnosis (which can make their jobs more complicated), the most commonly cited cause employees cited for experiencing negative judgmental feelings were specific client characteristics (personal, professional, or relational). Thus, the worker can perceive the client's personality, past job or career(s), or the type, quality and/or quantity of past/present relationships negatively. I heard workers espouse negative feelings towards individuals because they were alcoholics, addicts, sex-offenders, convicted felons, treated loved ones poorly, or whose parenting skills they deemed inferior. For example, nurse Charlene told me about a patient that:

> drank like a fish and was leaving all the housekeeping and income needs to her 15 year old son. I was so angry watching how he couldn't grieve or get support because he had to be the parent. My care wasn't less, but I definitely felt like a wall was kept up inside of me.

In short, these patients are not individuals who workers would *choose* to be a part of their personal lives. As patients, however, the worker is required to not only make the individual comfortable, but is also required to adhere to the individual's wishes and desires as well. In other words, engage in kindnesses and niceties for people they would choose as friends. Such a dynamic can invoke negative feelings in workers and will often prevent them from relating.

Yet, failing to acknowledge or take into account their own personal values and beliefs carry consequences pertaining to relating as well. For example, when I asked nurse Mary if there were ever a time that she felt detached from, or unable to relate with, a patient, she explained it this way:

> Yes, when caring for a pedophile who happened to also be a priest. I've cared for hundreds of patients who have led unscrupulous lives, and it has never affected me. I know I’m supposed to remain non-judgmental, but this guy, this pedophile priest, showed no remorse. He gloated! Yes, of course I knew he was sick, but I just couldn’t overlook what he’d done. It would have felt like selling my soul to the devil.

In this case, Mary was well aware of the importance of remaining non-judgmental, but with this particular person, her personal beliefs and values were pushed to their limit. Suspending judgment about who this man was and what he had done would have resulted in her failure to relate compassionately.

The final barrier to relating that emerged in my data was concerned with relationship length. As discussed previously, hospice service is delivered in one of two different ways—in the home or through inpatient care. The type of client relationship that the hospice worker engages in differs depending on which of these environments the worker is employed. In-home patient care generally translates to longer and more personal relationships between the worker and the client, while inpatient care entails short term, less personal relationships. Clients receiving home care can easily be on service of months, and in some cases a year or more. Based on employment turn over, a client’s hospice team may remain the same the entire time they are on service, with nurses, aides and social workers visiting the client anywhere from several times a week to bi-monthly. Conversely, inpatient clients usually stay at the inpatient unit for only a few days to a week or two at the most.

While most workers have a preference for one work environment over the other, each carries the potential to impede compassion. For example, inpatient workers have stated that “Given our short time with people, you know sometimes I’ll only see them once or twice, I am often detached…I need more time to connect” (CNA Summer), and social worker Sarah, who works in the field stated that:

> I have a difficult time sustaining a high level of involvement with patients whose disease process is slow, long, and has long periods of stability, like heart disease. Their need for services wanes and then escalates over a long period of time. It’s exhausting and I find myself turning off.

It should be noted that both Summer and Sarah work in the environment that they prefer, yet both of them nonetheless suggest that relationship length can interfere with the experience of relating. Meanwhile, social worker Leah, who prefers the field yet was working at an inpatient unit, described the difference in relationships this way:

> Inpatient social work is deathbed social work, while field social work is more relational, it’s, you know, kind of a more-long term, so there is emotion work involved in both of these, it’s just different. For me, I need the length of time with my patients and families in order to be able to connect. And that is what I love about the field. Some of my patients would live for months or longer, and I really felt like I knew them in their own environment. It was wonderful to just watch them interact with their families in comfortable settings. Here [the inpatient unit], what I like is

> that families are here a lot. So I keep in regular contact with all my families—everyday—even though I'm not required to see them or talk to them everyday. Things can change so fast here, I just don't want to miss anything. Whereas, in the field, even though I only see my patients or families once or twice a month, because they are serviced longer, I still feel like I can get that connection here if I make the extra effort to reach out even when I don't have to.

Leah clearly describes how she manages the tension between length of time with her clients and her ability to relate with her clients.

Summary of Relating

Similar to how hospice workers described the process of recognizing on a cognitive and intuitive level, they described relating both cognitively and intuitively, as well as identifying a third level, that which occurs through reciprocal acts of compassion. Table 6.1 below summarizes these findings.

6.1 Summary of Relating

Theme	Strategy	Behavior
Cognitive relating	Looking/listening for connections	Actively looking for connections
	Reducing uncertainty	Disclosing personal information to reduce uncertainty
	Taking time to develop trust	As trust grows, so too does the interpersonal connection
	Embracing difficult situations	Difficult patients and/or situations as a means to creating a sense of closeness
Intuitive relating	Feeling like/seeing that someone needs me or that I made a difference	Being drawn to a patient/client and is seen as mutually beneficial
	Identifying and identification	When client or situation reminds them of someone they know/knew
	Spiritually and through instant connections	Beyond skill, a sixth sense. Relating as a spontaneous gift
Reciprocity and acts of appreciation		Witnessing others/another's act of appreciation triggers compassion
Barriers to relating	Boundaries	Failure to maintain boundaries w/clients could lead to burnout and impede relating
	Judgementalness	No accepting people for who they are/letting personal feeling get in the way of relating
	Length of relationship	Spending too much time with one client, or too little time with a client can interfere w/relating

At the cognitive level, workers might actively seek bonds with their clients by carefully looking and/or listening for connections. Sometimes relating was facilitated through implementing uncertainty reduction strategies, such as disclosing personal information about themselves as a means of putting their clients as ease. They also cited situations in which they needed to take time to develop trust, acknowledging that relating can be an outgrowth of the time it takes to develop interpersonal relationships and connections. Lastly, and not unexpectedly to arise in regard to human service work and workers, my respondents talked about difficult situations and/or patients as those that lead to a special sense of closeness.

At the level of intuition, hospice workers talked about relating in three ways. First, visual or visceral evidence that they had made a difference in their clients life, could lead to feelings of connection. Next, they described identification as a means of relating. When clients or situations reminded them of someone or something from their past (or present), it could lead them to desire and/or recreate those bonds/relationships that feel/felt good or familiar. And finally, my participants described spiritual feelings and instant connections as tacit/somatic relating experiences. The third and final level of relating that my participants talked about occurs through reciprocal acts of compassion. In these experiences, workers identified witnessing compassionate acts in their clients or receiving acts of compassion from their clients, as extremely powerful means of relating.

With regard to the barriers to relating that emerged in my data, workers discussed three issues in particular. First, they talked about the importance of boundaries, both the need to establish and maintain boundaries in order to prevent burnout, as well as the danger in maintaining boundaries that are too firm. Either of these situations could lead to workers not being able to fully engage the relating process. Secondly, they discussed judgementalness as a potential impediment to relating. Workers talked bout the need to suspend judgment, yet not compromise their personal values and beliefs. Workers will inevitably encounter clients who engender negative feelings in them, which can potentially prevent them from relating with the individual. And lastly, my participants alluded to the relationship length that they have with a client as a potential barrier. Depending on the individual workers preference, caring for a client for a very short period of time, or for a very long period of time, can prevent the worker from relating and connecting. I will now move on discuss the final sub-process of the compassion model—responding.

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[1] The claims of authenticity made by a number of my participants struck me as complex and somewhat problematic. I address in detail these issues in my discussion of limitations and future directions in chapter seven.

[2] The actual terms that workers used to describe these experiences, and which I refer to as identification, were ‘transference’ and ‘counter-transference,’ terms from psychology and (most) often used by hospice workers interchangeably. In very short psychological terms, transference refers to a situation in which someone says or does something that reminds you of your past. Counter-transference is a clinician’s reaction to your transference (Conner, 2009). So, if the terms were being used correctly, workers would experience transference when a client reminded them of someone or something from their past, and counter-transference when a patient was experiencing transference towards them and they

were then reacting to that patient's transference. Although my participants were as likely to use one term as the other, and hence the reason I have chosen to reframe the idea as identification, they usually meant that they were experiencing transference towards a client.

[3] Regardless of circumstance, pediatric patients are the most emotionally wrenching clients for hospice workers—there are fewer sense making models available to explain a child's death. Fortunately, pediatric patients were an anomaly for the agencies I worked with. Yet, nearly everyone I spoke with had a story about a child to tell. In fact, the workers at one of the inpatient units I conducted participant observation at, talked about a little girl that died at the unit a number of years previously. They said that her ghost regularly comes back in the middle of the night to the room where she died. I arranged to come in very late one night and sit in the room and wait for her. But alas, she did not make an appearance that night—or at least not one that I perceived.

[4] Although nearly all hospice workers I spoke with either inferred or directly stated that they did not fear death, I nonetheless noticed a number of situations in which individuals clearly did not want to be reminded of their own mortality.

Chapter 7

THE PROCESS OF RESPONDING

The third and final compassion sub-process is responding. Kanov *et al* explain that besides noticing and feeling another's suffering, compassion necessarily moves an individual to want to ease or alleviate that person's suffering. These researchers define *compassionate responding* as "any action or display that occurs in response to another's pain, with the aim of alleviating that pain or helping the sufferer to live through it" (p. 814). They argue, however, that not all behaviors can be considered compassionate. In order to be considered compassionate, behaviors must be accompanied by noticing and feeling. As with their conceptualization of feeling, Kanov *et al*'*s* conceptualization of responding has some confusing parts as well. For instance, they state that responding can come before feeling (action before feeling), yet argue that responding is an indicator of feeling (feeling before action).

Again, Miller seems to alleviate some of this confusion when she frames connecting as a relational/interpersonal concept with *links* to the process of responding. She defines responding as "actually behaving or communicating in ways that could be seen as compassionate" (p. 233). In other words, what constitutes a responding behavior resides in the eye of the beholder, a conceptualization that more accurately coheres with Weick's (1995, 2001) model of organizational sensemaking. According to Weick (2001), particularly in situations consisting of ambiguity and uncertainty, individuals come to understand and make sense of their situation retrospectively, an idea that Weick encapsulates in the phrase, “How can I know what I think until I see what I say” (p. 189). While Weick’s model of sensemaking is clearly more in line with the findings I gleaned from my participants, at least with regard to hospice workers, Miller’s definition of responding doesn’t go quite far enough.

Both Miller and Kanov *et al* acknowledge that responding need not yield tangible results that actually alleviate another’s suffering, and it was clear in my research that workers recognize this fact as well. As social worker Sarah stated, “When I first got in to social work, I wanted to save everybody. But now, you know, I realize that just isn’t possible, and I’m OK with that. As long as I feel in my heart like I did my best, that’s all that really matters,” and nurse Irene agreed, “It doesn’t mean that you actually have make people feel better, just that you want to try to make a difference in some way.” However, as I will discuss in greater detail a little later in this section, recognizing that they may not be able to ‘make it better’ goes one step further for hospice workers. For hospice workers, doing “nothing” is, in fact, an interpersonal and organizationally valid response—a response that cannot be “seen as compassionate” by anyone other than the individual making the decision to do nothing. For example, a worker may decide that the best course of action for a nonresponsive client, who is resting comfortably, is to do nothing. The decision to do nothing can be a conscious decision based in skill, training and intuition. An outsider would likely not view the situation as a compassionate response, but the individual worker (as well as other hospice workers and the organization) would understand it as such. Therefore, I believe a better way to understand *responding* is as engaging in behaviors or communicating in ways that are seen, or could be seen, as compassionate by the person responding, another individual and/or the organization.

As with the sub-processes of recognizing and relating, both cognition and intuition were evident in hospice worker's responses to their clients. Yet, as I will explain, I initially found the "responding" sub-process to be one of the most difficult to pin down. Human service work in general is about action—doing, engaging, helping, etc., —and examples of such behaviors were everywhere in my fieldnotes and interview transcripts. Once I began the task of coding my data, I realized that identifying conceptually separate and unique categories of responding would not be easy. Yes, the categories of 'cognitive' and 'intuitive' were immediately evident in my data, and workers often talked about specific responses and/or targeted actions in isolation ("I do this or that"). For many hospice workers, however, responding was often framed, articulated, and/or enacted quite broadly, as a fluid and holistic concept. I soon realized that, for many of my participants, the *only* way to understand the sub-process of compassionate responding was holistically, encompassing the entire individual and/or encompassing other concepts. It wasn't about a specific action or behavior aimed at a specific part of an individual or illness. Holistic responding is also the first of the responding themes that I will talk about, before moving on the cognitive and intuitive responding.

Holistic Responding

One of the questions I asked respondents, either directly or indirectly, was what compassion meant to them, and/or how they communicated compassion to their clients. And perhaps not surprisingly, responses to this question, or type of question, yielded remarks directly pertaining to the process of responding. Often, however, the idea of responding was articulated quite abstractly, as when social worker Brian said, “Just show them [clients] that you care. That’s all they really need,” CNA Faith simply stated, “I just want to make a difference,” and nurse Daniel offered, “I’ll do whatever it takes to sooth their soul” And nurse Carrie defined compassion as “a full service mission. It means giving all you’ve got to someone and making them feel special.”

For a great many workers, their response to not only this question/concept, but also any number of others, indicated that responding was not something that could be talked about in isolation or as a concrete ‘I do this and I do that.’ For example, when I asked nurse Janet what component of her work most energized her, she said, “I’m energized by the simple things that I can do. Like, whether I am able to relieve some distressing symptoms, or allowing them [patients] some final dignity and quality in their life, or in some way enriching their final days.” While none of the issues that Janet talks about seem all that ‘simple’ to me, for hospice workers, they are the very core of a compassionate response. It isn’t so much about the specific actions or activities as it is about understanding their clients (and their client’s condition) on a holistic level. Nurse Irene put it this way when I asked her how hospice nursing was different from other types of nursing:

> It’s different in many ways. You rarely treat the patient in isolation; they are always part of a larger system and even if they have no living relatives

> around, you deal with the memories and the ‘baggage’ of the family of origin. You spend as much time dealing with psychosocial issues as you do with the physical aspects of dying. You really get to know your patients. That’s what you do—you get to *know* your patients.

Nurse Mary indicated that the most important component of a compassionate response was the heart. She said:

> You know, um, because your head says—I don’t know—your head knows stuff. But if your heart doesn’t know it, it’s a hard thing to teach. You know, you can’t teach the heart. Everything else will come. You’ll learn the medications. You’ll learn the routine. You’ll learn all the hospice stuff, but you can’t teach the heart; so I think that’s where it starts and ends!

Mary’s response suggests that doing ‘things’ is perhaps the easier part of the job because skill is learned. But a compassionate response goes to, or necessitates going to, a deeper level—a level beyond skill. Meanwhile, social worker Beth said that the most important thing she needs to do is open herself up to her clients so that she can:

> Hear them, hold them, and be there for them no matter what they were before being a hospice patient. I give them my arms around them, my words to comfort and my hand to hold when things get tough, my shoulders to lift off some of their burden and my eyes in the world outside their window to share with them to give them something else to focus on.

In this excerpt we see that, at least metaphorically, Beth engages *all* of herself (ears, arms, words, hands, heart, shoulders, eyes…) in order to attend to *all* of her client.

Spiritual care provider David's conclusion in the following narrative clearly conveys the idea of holistic responding. David, who I interviewed at an inpatient unit where he spent part of his days, described what a typical day might be like for him at the unit. He stated:

> I walk in here, and I never know what might happen. Sometimes I just come in and share some poetry or sing some songs, read some scripture—just be with them for a little while. My role is to provide the environment for people to go to that spiritual place safely, so it feels safe and nonthreatening. People talk to me about things they would not talk to anyone else about. For whatever reason. It is a very holy moment. I mean, to meet somebody very briefly, that is only here for two or three days, to go into those intimate places where they have some regrets or something. Whew! That's what it's all about…nothing and everything at the same time.

Given that the discourse of hospice in general is one of holism, my participant's responses, which ground the nature of their work in holistic care, might come as no surprise. However, what makes this noteworthy and unique is that holism really only surfaced as a significant idea when it came to my analysis in terms of responding. In other words, the idea of holistic recognizing and/or relating was/were not articulated in the narratives and/or interviews with my respondents.

Cognitive Responding

The largest category related to compassionate responding that emerged in my data is cognitive responding. Hospice workers report a multitude of ways in which they respond to their clients needs by actively thinking about the best way to meet those needs. At the level of cognition, I found that my participant's compassionate responses fell into three sub-categories of behaviors: verbal, non-verbal, and action oriented. Although the categories are not mutually exclusive (e.g., action oriented behaviors include elements of verbal and nonverbal communication), workers articulated their responding behaviors as if they were distinct or somehow discrete activities.

When workers talked about responding verbally, they indicated that quantity and/or quality were less important than effort. What was most important to employees was that they at least put forth effort, because they viewed verbal responses to signify empathy and presence. For example, when I asked CNA Katie what compassion meant to her, she replied, "It means that I am present in mind and behavior. THEY may or may not be talking—or even aware—but I am still talking, because that is how I make my presence known. If they are hurting, I'm responding verbally." Social worker John further explained that responding verbally wasn't solely directed at the patient, but others as well. He stated, "I can help my patients by speaking up. If I disagree with the doctors or with the family members, I don't hesitate to speak my mind. Of course, always on behalf of my patients." And social worker Sarah told me that she has been known to go in to a nonresponsive patient's room, sit with them and "Read. Anything and everything.

I mean, when I'm too tired to come up with conversation or things to say, I've just sat there and read the lotion bottle ingredients to them. I'm hoping that they can feel that I am there with them and that I care."

Many of my respondents talked about just being there and/or making their presence known in terms of nonverbal responding as well. For example, when I asked spiritual care advisor David to explain what his job was, he said, in part:

> If people know the chaplain's coming, then I don't need to do too much. My title, who I am, my presence, my persona, what I represent, all speak for themselves. As far as religion and spirituality and the like, people will just know why I'm there. And it will be like, they don't need for me to do much more than be there and that doesn't mean that I have to do or say anything in particular.

Nurse Dianne, in talking about the helplessness she sometimes feels, said,

> In hospice there are a lot of times when there isn't anything you can do other than be there for support. You watch a patient go through an extremely long and agonizing death and wish you could ease it, but when the meds don't work, all you can do is be there.

And somewhat similarly, in her response to my question about what compassion meant to her, nurse Irene replied, "To me it means being there for someone. I try to be compassionate to people by letting them talk and not judging them." So, in the case of David, Dianne, and Irene, one way to respond was through presence and 'being there,' which, for them, is a communicative response, just not one based on language. In both cases, the verbal component (or verbal burden, so to speak) resides with the client, not with them. In the case of David Dianne, and Irene, they clearly indicate that what they do—be there/be present—is not the same as listening. Listening is, however, another nonverbal communicative response my respondents used.

Listening emerged as not only a component of the compassion sub-process of noticing, but as a strategic, communicative *response* as well. For example, when I asked social worker Annie if she felt differently about her job from when she first started, she said, “Well, I don’t know if I feel differently about it so much as understand it differently. Now, I see so much more clearly that my primary role is as a listener…to listen to stories, to listen to the patient and the family. I can be of the most help and comfort by just listening.” And nurse Diane said the primary way that she conveys compassion is by “listening primarily. Not being the center of attention, not doing all the talking. Just listening.” In response to that same question, nurse Janet stated:

> Although I am a toucher and hug or touch a lot, um, I think I really try to just listen. That is how I try to convey compassion. Even though you can’t change anything, but just holding their [patients] hand and listening to them is big, because you are taking time to listen to them. So when everybody, like their family members and friends, are all trying to keep them up and trying to keep them cheerful all the time, well, it’s hard for family members to sit down and talk to their loved ones about dying. And really that is what they [patients] need…they just need time for someone to just sit and listen to how they feel.

Thus, listening at the level of response is less concerned with the content of what is said by the client (which is a focus when workers use listening as a strategy for recognizing a clients' need). Rather, listening in terms of responding is, essentially, an end in and of itself. In short, listening to notice implies or requires further action while listening as response does not.

Lastly, nurse Janet's response above alluded to the way in which touching functions as a form of nonverbal responding as well. Of course, much healthcare work is touch. But there is a difference in the use of touch to provide care—which is clearly clinical in nature and generally involves wearing gloves—and touch as a compassion response. Workers talked about how they used physical contact "like handshakes and touch" (social worker Beth) or "hugs and kisses, lots of them" (nurse Diane) as a means to show they care, not to simply and solely provide physical/medical care.

The idea of touch as a response was not only talked about in literal terms, but figuratively as well. For example, nurse Carrie, who had recently transitioned from a job as a midwife to hospice nurse, stated that the major difference in jobs was that as a hospice nurse she is "a hand to hold during life's transitions," while spiritual caregiver Marcy said that "I always tell people, I'm here for you to lean on."

The final category of cognitively based responding strategies that I identified in my research are those I call action-oriented responses. Action oriented responses certainly can be verbal or nonverbal as well, but additionally they are responses that are more involved, requiring ongoing action/activity, or are reciprocal in nature (requiring input or acknowledgement from the client). In other words, action-oriented responses are conceptually distinct from strictly verbal and nonverbal responding.

For example, social worker Sarah described one component of an inpatient unit social worker's job. She said that patients/families often arrive at the unit thinking that they will be able to stay at the unit until they die.[1] She explained:

> Part of the reality of working at the inpatient unit is that your role is to help the client make sense and understand that this is just a short-term place. There is this misperception that, you know, now that I am on hospice I get to stay at this nice beautiful care setting, in a private room at no cost, however many weeks or months it will take. So my first and primary role is to teach and advise them on all of that, correct the error in their thinking and then assist them in looking for other options.

In this case, Sarah sees her compassionate response as one that is multi-layered and ongoing. As she states, she first engages in sense making, then teaching, then advising, and finally in facilitating and meeting the practical needs of her clients (i.e., arranging for the appropriate services, finding care facilities, etc.).

Like Sarah, many other individuals talked about responding in terms of teaching and/or empowering their clients in ways that were clearly action oriented. In other words, they indicated that this action went beyond simply responding with words that imply something should or could be done, but was more like being a co-participant in the family/client situation. Social worker John, in defining compassion, put it this way:

> Compassion is loving and teaching and empowering my clients. Sometimes I cry with them and sometimes we laugh. But I NEVER say ‘I know just how you feel.’ What an insult that is! I do say ‘I hear you.’ When I say that, they feel like, ‘yeah, I’m still a person, I’m still in charge of my life.’

Likewise, social worker Leah described a particularly tenuous balancing act that social workers go through with their newly admitted clients—trying to figure out how much (truthful) information the client is ready to hear. In the end, however, Leah said that preparing her clients for the inevitable was of utmost importance because:

> It is so hard to have a family come back to you after all this time and say, “you never told me it would be like this.” And that can hurt because I had grown close to them by then. But you know, most of the time I DID tell them and they just couldn’t hear it at the time. So I always try to formulate my conversations in a way that I get them to restate what I just told them. I think that helps it sink in. You really have to assess each situation carefully though because you don’t want to shock or overstress somebody who is already stressed out. But when it comes down to it, that’s the social workers job; to help prepare them for whatever is to come.

Leah later explained that preparing and/or educating her clients on their condition and what was and would be happening wasn’t a one shot deal. It meant that she needed to stay in contact with her clients so that as things changed, the preparing/teaching component of her job would continue. Hence, responding included maintaining contact. She said, “I like to check in and give my families a little update daily if I can. Even if its just two minutes, they feel like we really care.”

Along these same lines, workers talked about responding in terms of showing understanding for their clients, whether it is their physical or emotional condition. Spiritual care provider David described one type of compassionate response to show understanding that he has used with clients in the past. He explained

> Most people die the way they lived—they don’t change much. So I don’t try and change them either. Sometimes, you know, they come in here and have a regret or an offense that they need to be forgiven for, well I’m no judge. I believe in God and forgiveness, so I just accept them the way they are. I figure out what they need, and how I can let them know that God forgives them. And its important that I do that, you know, let them know that God forgives them. Whatever their transgression or sin might be.

Likewise, nurse Mary said that one of the things that she always tries to do is:

> Take the time to try to understand the other person's concerns and feelings, and living conditions, and to show them unconditional acceptance. When I do this, when I try to understand their position and don’t judge them, then it inevitably empowers them to make decisions on their behalf or for their loved ones.

And social worker James defined compassion as “knowing when to be silent and listen, knowing when to talk, but above all, it means showing support and understanding of someone's pain whether physical or emotional.” The nearly universal characteristic of the ‘show understanding’ response, however, was that workers applied it to individuals whom they may have had in the past who they either did not particularly care for, or that they wanted to blame for their own illness, such as lifelong smokers who were dying of lung cancer or alcoholics succumbing to liver disease. Most people, including me, would never assume that a worker would ‘like’ every client they had. But many hospice workers said they felt as if they *should* like everyone, even drug addicts, pedophiles or domestic abusers. Liking, it seemed, was intricately linked to compassion for many workers. In other words, the data reveals that feeling compassion is linked to if liking. And, as I noted earlier, hospice workers believe that compassion is the most important quality they can possess.

Additionally, although workers tried not to blame the patient for their illness, that wasn’t always such an easy thing to do. A great many individuals come to hospice with conditions that are clearly brought on or exacerbated by their own lifestyle choices. If either of the above situations (disliking a client or blaming them for their illness) did not act as a complete barrier to compassion for the worker, then the worker often stated that suspending judgment and showing understanding is their ultimate (and selfless) compassionate response.

Another example of action-oriented responding that I identified had to do with workers following the lead of the client. They stated that one of the ways in which they formulated a compassionate response was to either ask directly, “what can I do for you,” or indirectly take and follow the cues given by their clients.

CNA Summer told me, “You know, you just gotta allow them to be themselves. Pay attention to them and then mold your actions and responses around them.” Social worker Annie said that when she gets a new client she starts “where the client is at. I listen and then walk the journey with them. If they are comfortable, I let them tell me what they need or want.” CNA Susan told me about a patient who:

> Struggled in waves like a roller coaster with her illness. Sometimes, people who are in a lot of distress just don’t want anybody around. But when she was really bad, I would sit and sing to her and it seemed to soothe her. So I learned to just follow her lead when I was there. I would kind of start humming, and if I noticed her responding to my humming, then I’d start singing.

Coulehan (2009) argues that suffering brought on by trauma, illness or bodily degeneration, is existential in nature and does not necessarily parallel the individuals’ physical or emotional state. Hence, healthcare professionals need to rely on not only skill and knowledge, but must learn to engage with the patient at the existential level by first thinking and acting through reflexivity and self-understanding. Coulehan uses the term “compassionate solidarity” to convey this idea, and the ways in which my participants talked about responding to their clients by following their lead, clearly echoing this concept. Summer, Annie and Susan’s responses above, show that they understood that what a client may want or need, goes beyond skill and ultimately rests with the client.

The last, and perhaps the most counter-intuitive of the action oriented responding behaviors that emerged in my data was strategically doing nothing. The necessity for hospice workers to constantly access and reassess their clients' needs, which can change by the minute, means that their responses may need to change as well. And sometimes, doing nothing is what they do. Far from the absence of action, for many hospice workers doing nothing is a strategic activity. It can be a singular response, or it can be the response that takes place between other responses (i.e., "My client needs to be left alone right now, so I will check back later"). In either case, it was clear that, for my participants, they choose "nothing" not because they did not know what to do, nor was it akin to withholding or denying care.

In contrast, "nothing" was the appropriate care called for in a specific situation, and hence, frequently articulated as a skill. Nurse Hannah, for example, once explained how when assessing the needs of a patient, there are times when "I know there just isn't anything I can do. So I respect that and don't do anything. I just give them their space." And nurse Charlene told me about the depth and breadth of topics and conversations that she engages in with clients:

> So sometimes you have to let the conversation evolve. It may start with the meaning of life stuff. Or we may talk about art, poetry, music. Or sometimes it is deeper—they think they're either dying too soon, or they're not dying soon enough. But I know that I can't always make it better for people. I can try, but sometimes I know that it might just be best for me to let them be. There are things and journeys that some people need to do alone.

In both of these examples then, Hannah and Charlene explain how they assess each client and situation individually and determine that the appropriate (and compassionate) response is to leave the patient alone and/or give them time and space—in other words, do nothing, a communicative response that they describe in terms of action.

Intuitive Responding

Workers also describe responding intuitively. Intuitive responding represented a relatively small category of responses, perhaps because, as noted previously, hospice work is largely skill based—focused upon knowing (cognitively) what to do. Yet, workers offered examples of intuitive responding that were clearly significant to them. For example, social worker Beth told me about a patient that she had grown very close to. The woman was dying from ovarian cancer and toward the end her pain became increasingly difficult to manage. Beth recalled:

> Not only did I care so much for her [the patient], it was the first time I'd seen someone in that much pain. You know, usually, most patients are in good pain control, but she was crying and saying how much she hurt. I didn't know what to do. So I just grabbed my phone right then and there and called her nurse, who later thanked me and told me I'd done the right thing. I was glad that I didn't let foolish pride get in the way and that I just followed my heart.

The significance of this experience—and Beth's reference to foolish pride—has to do with the fact that as a social worker, pain management is not specifically within Beth’s purview. Many social workers state that they believe that their work and contribution (psychosocial) to the hospice team is not understood and/or appreciated by the medical side (nurses, CNA's).

I got the feeling from several of the social workers that they felt they had to really ‘prove’ their worth to the rest of the team. Beth was one of the social workers who felt this way. So in Beth’s example, following her intuition turned out to not only be the right thing to do, but also showed her that she didn’t have to solve every problem to be validated by her co-workers.

The intuitive responding dynamic was most evident when I asked workers if they could recall a time when they didn’t know what to do, and if so, how they approached the situation. Responses were fairly evenly split between three groups: 1) those who indicated they’ve mostly known what to do in any/every situation; 2) those who offered a cursory, “Sure, it’s inevitably going to happen” type of response and then moved on; and 3) individuals who recounted very specific situations that left seemingly profound impressions on them. In the last case, participants overwhelmingly indicated that they let their intuition guide them.

For example, social worker Annie stated, “Since there are so many different situations and family dynamics, I’ve found that there are many times when I didn’t know what to do. I those cases I usually just follow my gut.” Nurse Carrie told me about a recent inpatient unit experience:

> I walked into this room and I had a family just sitting vigil. One of them asked, “How will we know when the miracle has occurred?” I asked what

> he meant by that, and he said, “We have been praying for a miracle and we want to know what to look for.” Ugh! I didn’t know what to say to that! So I took a deep breath, said a little prayer of my own that the right words would come out, and replied, “He is dying without pain and without fear and surrounded by a family that loves him. THAT is a miracle.”
>
> There was this collective sigh in the room and the family just completely relaxed, and the man died a few hours later.

So, in this example, Carrie explains how she relied on intuitive praryer to help her address and respond to an issue that she had not encountered before (or perhaps ever would again). It also highlights the way in which hospice workers have to deal with issues outside their particular specialty, and hence, can produce anxiety. Like social worker Beth’s experience cited earlier, in which she was presented a medical issue, nurse Carrie was presented an issue more suited for a social worker, that she needed to address. Although not all workers reported “happy endings” to their compassionate responses, in both Carrie and Beth’s case, the experiences were positive. And as with recognizing and relating, workers do experience barriers to the process of responding, which I will discuss now.

Barriers to Responding

My data revealed that adaptability and flexibility acted as a potential barriers to the process of compassionate responding. Workers often talked about the need to remain flexible. Because their clients come to them with unique and highly individual circumstances, each and every case requires that they be able to “bend and work with families” (social worker John). Yet, the counterpoint to flexibility—rigidity—was deemed necessary, to some degree, in order to “be able to stay strong and be in control” (social worker John). In other words, to meet the compassion demands of hospice work, hospice workers need to be flexible enough to (potentially) craft a different response with each and every client each and every time, while retaining enough rigidity that they feel in control of the response.

Although rigidity at first sounds similar to the barrier to relating discussed in the previous chapter (boundaries), it is articulated differently. Boundaries serve a protective factor against burnout (akin to an emotional contagion). Rigidity, on the other hand, is usually talked about in terms of maintaining professional skill and control, or at least the appearance of skill and control. One of the most unique and powerful draws of hospice work is that hospice workers are viewed as the ultimate authorities on all things related to death and dying. Other than the specific hospice’s organizational hierarchy, hospice workers have a great deal of authority, autonomy, and control over their day-to-day and client-to-client activities. It is not unusual for doctors to defer to the opinion of the hospice worker—something clearly unique in the healthcare field. Or as nurse Irene once described the difference between hospice and other types of nursing, “You really get to know your patients, and the doctor says, ‘you are the expert.’ That really makes the job easier you know—when the doctors treat you with respect!” Loss of that (either real or perceived) authority and control can negatively impact workers and the way they feel about their jobs, and hence, the ability to engage in compassionate responding.

An example of the fluidity/rigidity tension can be seen in a story told to me by social worker Sarah. She worked with a female patient with cancer who lived in a rather remote area. When traveling to visit the patient, the woman's husband met her at the property's gated entrance in his pick-up truck and drove Sarah to the house. On the drives to and from the house, the man spoke about things that Sarah felt were clearly inappropriate, such as details of the couple's current and past sex life. Although the conversation made her very uncomfortable, she never confronted the man or told him to stop, because:

> I didn't know the man or this couple before, before illness. I didn't know whether this type of talk was normal coming from him, but I suspected that, and I see this a lot, that it was his way of dealing with his fear or stress or anxiety or something. You never know how someone is going to deal with things and you just have to go with it sometimes. I mean, you know it is going to end eventually. And while he was technically my client as well, my real duty was to her, the wife and if I let him get to me, then I knew I wouldn't be able to be there for her. So what I finally decided to do was bring a little hand-held tape recorder with me. I told him that Judy [the organization's area manager] decided that transcribing notes would be easier and more thorough if we recorded our meetings with our patients. Well, guess what…that ended the sex talk! A little creative thinking and I don't look uncaring but like the consummate professional.

In this except then, Sarah tells how she remained flexible in meeting client needs, yet found a way protect herself and her professionalism. Too far one way or the other, and Sarah believed she ran the risk of not being able to "be there" for, and respond to, her client.

Summary of Responding

Like recognizing and relating, hospice workers describe cognitive and intuitive aspects to responding. They also talked about the sub-process of responding in a third way as well—holistically. Table 7.1 below provides a summary of these findings.

Table 7.1: Summary of Responding

Theme	Strategy	Behavior
Holistic	Individual/situation as complete/ complex system	Responses described in the abstract and addressed holistically—"my heart knows what to do."
Cognitive	Verbal	Verbal responses imply empathy and presence—quantity and quality less important.
	Nonverbal	Makes their presence known
	Action oriented	Involved, detailed, complex, and/or ongoing long-term responses.
Intuitive	When cognitive skills/knowledge don't apply	Relying on instinct, gut or heart to guide them.
Barrier to responding	Adaptability/rigidity	Remaining too rigid or inflexible interferes with the ability to respond appropriately

Perhaps not surprisingly, given the holistic discourse that surrounds hospice work, individuals often described their responses to clients or particular situations holistically. At an abstract level, they talked about responses that included ‘soothing the soul,’ and ‘giving all you’ve got.’ Other times, workers implied that clients and situations were too complex to talk about in isolation or that there was one particular thing that they could do to address the needs of the client. In this case then, workers described responses that would relieve distress or provide their patients with added dignity and quality of life.

Compassionate responding at the cognitive level manifested in three ways: verbally, non-verbally and action oriented. Verbally, individuals stated that quantity and quality were less important than putting forth the effort to respond verbally, as verbal responses conveyed empathy and presence. Workers also alluded to the idea of presence with regard to non-verbal responding as well. They stated that ‘just being there’ or ‘really listening’ was often the most important thing (and sometimes the only thing) they could do for their clients. Action oriented responses included things that resided in the realm of skill and entailed ongoing or sustained action or activity. In these instances, workers talked about complex or detailed experiences that included teaching, educating, preparing and/or empowering their clients.

The third and final level of responding—intuitive responding—was the least cited of the responding behaviors, perhaps due to the nature of hospice work being knowledge and skill based. When my participants did discuss intuitive responding, it was usually in response to a question about how they approached situations in which they were unsure and didn't know what to do. Many described responding from the heart or following their 'gut,' and reported positive results when they did engage their intuition.

With regard to barriers to responding, workers alluded to adaptability as an issue that could interfere with their ability to craft an appropriate response. Hospice workers discussed the need to remain flexible enough to craft a different response with each and every client each and every time, while retaining enough rigidity that they feel in control. In the next and final chapter of this dissertation, I will summarize my data and findings and explicate what I believe to be a more complete and finely nuanced representation of the compassion process. And lastly, I will conclude the chapter by offering some practical implications and discuss the limitations and future directions implicated in this study.

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[1] As previously noted, inpatient units are reserved primarily for patients who need symptom management or respite care. The average stay is a few days to a week, rarely longer. Although, at one unit where I volunteered, at least two patients were at the unit for several months: one man who could afford to pay, out of pocket, for an ongoing private room, and a young woman who had grown to be loved and adored by (most importantly) the unit manager, who allowed her to stay at the unit until her death. The fact that so many people die at the unit is not a reflection of the length of time they are there as much as the fact that they are close to death when they arrive. However, all the inpatient units that I have seen are very warm, welcoming, and homey—quite inviting places that many patients and their caregivers would like to be able to stay indefinitely.

Chapter 8

CONCLUSION

> *Debbie: So, what qualities do you think someone wanting to work in hospice should possess?*
>
> *Dianne: Well, they should be intelligent, creative and be able to think critically, have strong nursing and assessment skills, be open-minded, get along with everybody, have patience, a sense of humor, be assertive and have good communication skills. Be able to work independently as well as part of a team, be able to read a map and carry bags of supplies. You need to be able to leave your problems at the door, be able to handle death and dying, have balance in your life and a strong support system. But of course, most importantly, you need to be kind, compassionate, caring and empathetic.*

Dianne's response to my open-ended and somewhat ambiguous question, a question that I try to ask everyone who works in hospice, was not particularly unique—longer and more detailed than many, perhaps, but not drastically different from any other person's response. Clearly, hospice workers understand and articulate the work they do quite holistically, as work that includes facets of knowledge, skill, and intuition, and functions intrapersonally, interpersonally, and organizationally. Regardless of the depth and/or breadth of the individual's response to this question, the one overwhelmingly common quality that workers cite as necessary to their job is compassion. And while my scholarly predecessors provided immensely helpful conceptualizations of compassion that allowed me to meaningfully engage my data, my data and analysis extends, nuances and complicates the concept of compassion as theorized by Kanov *et al* and Miller. In this chapter I provide a summary of my data and findings and offer my contributions to a more complete and finely nuanced representation of the compassion process. I conclude the chapter by providing some practical implications, discussing the limitations of my data and research, and offer suggestions for future research.

Discussion and Contributions

In chapter three, I provided a review of the literature on both negative and positive organizational processes, and utilized the theoretical conceptualization of compassion as a three-pronged process of noticing, feeling/connecting and responding to ground these research questions:

RQ 1: What are the compassion processes of *noticing* that hospice workers describe in regard to their jobs? What are the barriers to noticing that workers describe in regard to their jobs?

RQ 2: What are the compassion processes of *feeling/connecting* that hospice workers describe in regard to their jobs? What are the barriers to feeling/connecting that workers describe in regard to their jobs?

RQ 3: What are the compassion processes of *responding* that hospice workers describe in regard to their jobs? What are the barriers to responding that workers describe in regard to their jobs?

In chapters five, six, and seven, I provided detailed analysis and examples from my fieldwork and interviews, which revealed that these questions and current conceptualizations of compassion were more complicated than originally theorized.

With regard to RQ 1, my analysis suggests that the term *recognizing* more precisely reflected this process than *noticing.* Recognizing, unlike noticing, entails identification with the target of compassion and implies that we must be able to understand and assign meaning to what we notice. Further, my data revealed that hospice workers discussed recognizing in two ways: 1) cognitively in which they actively engaged in searching out someone’s need, and 2) intuitively, which they describe as a “sixth-sense.” This differentiation is conceptually helpful because it shows how compassion functions at a level of active engagement and skill (cognitive), and tacitly (intuitive). In other words, in practice, it may be that cognitive processes could be one component of training. Workers also identified a number of organizational factors that they felt threatened their ability to recognize need, specifically: caseload, paperwork and regulatory requirements.

Moving on to answering RQ 2, I proposed that current articulations of the process of feeling/connecting, would be better served under the umbrella term of *relating*. Relating encompasses both feeling and connecting, while not privileging one over the other, or requiring both. Likewise, my participants described this process as both cognitive and intuitive. Cognitively, hospice workers actively sought bonds with their clients, while at the level of intuition they described relating that occurred more affectively and without conscious effort. My data also revealed a third way in which hospice workers related, which was through witnessing a third party’s act of compassion or being the recipient of a compassionate act that in turn triggered compassionate relating. Meanwhile, the barriers to relating that workers identified included the need to maintain personal and professional boundaries, the importance of remaining non-judgmental, and issues pertaining to the length of time a client is under their care (either too long or too short).

Lastly, with regard to RQ 3, three themes pertaining to responding emerged in my data. Like recognizing and relating, my respondents discussed responding both cognitively, as focused and frequently skill based responses to their clients, and intuitively, which they described as simply following their heart. The third theme of responding workers alluded I’ve labeled holistic responding. Holistic responding encompassed both cognition and intuition, but went a step further. Workers described their clients and their own behaviors in terms of totality in which attributes and behaviors cannot be isolated one from the other. The barriers to responding that emerged in my data pertained to workers desire to remain adaptable and flexible in order be able to craft an appropriate and potentially unique response for each client. Failing to remain adaptable enough to see potential options, threatened workers’ ability to respond appropriately.

Table 8.1 below summarizes the compassion processes as theorized by Kanov et al., and Miller, and provides my reconceptualization and rearticulation of the processes of compassion.

Table 8.1: Reconceptualization of Compassion Processes

KANOV		MILLER		WAY	
Noticing	Paying attention to others' emotions, and reading subtle cues	Noticing	Noticing not only the need for compassion, but noticing details about another's life so that the response can be the most appropriate	Recognizing	Identifying with the individual. Being able to understand and apply meaning to what we notice
Feeling	Feeling compassion for another's suffering (affective)	Connecting	Connecting with others (relational)	Relating	Identifying with, feeling for, and connecting with (affective, relational, & embodied)
Responding	Any action or display that occurs in response to another's pain—*must be* accompanied by noticing & feeling.	Responding	Actually behaving or communicating in ways that could be seen as compassionate.	Responding	Engaging in behaviors or communicating in ways that are seen, or could be seen, as compassionate by the person responding, another individual and/or the organization

Building upon these findings, my research suggests what I believe to be one other substantial contribution to the current theory of organizational compassion. Specifically, my data reveals that the compassion process, currently conceptualized as a three-pronged (and according to Kanov et al, linear) process, may not, in fact, be an accurate reflection of how compassion is communicated and enacted in some organizational settings. Instead, my data suggests that responding is the fundamental and key process, akin to an umbrella under which recognizing and relating function. This study illustrates the distinctly unique aspects of hospice work that brings to light the central role of responding.

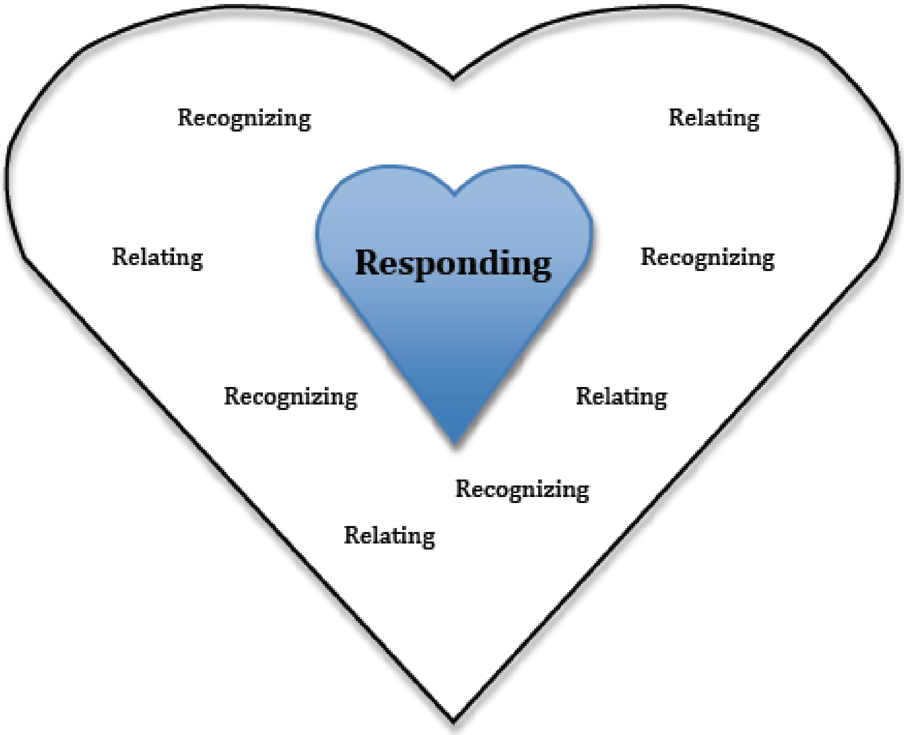
Recall the first two issues pertaining to the ways in which compassion has, to date, been theorized that I discussed in my findings preview at the start of chapter five. First, I noted the how suffering has been a key term utilized by scholars as a means to identify those individuals who are in need of, or deserve, compassion, and argued that hospice workers did not, nor would not, consider suffering to be a prerequisite of compassion. In contrast, my data suggests that any individual for any number of reasons could or should be the recipient of compassion, and this is one factor that highlights response (communicative action) as the most important process of compassion.

Secondly, I discussed the particularly slippery nature of the three interrelated compassion sub-processes and provided an example of how workers responses could come first, after which came recognizing and relating. And, at the beginning of chapter seven, I noted how I initially found the responding sub-process quite difficult to organize and make sense of. Understanding responding as a conceptually separate and unique component of compassion was far from straightforward, primarily because hospice work is “doing,” i.e. responding, work. In other words, most people would likely witness workers’ actions and assume that what they were doing was ‘the job,’ as opposed to ‘responding,’ a component of the compassion process. Additionally, many times the “doing” is doing for individuals who are not only nonresponsive, but also are often individuals with whom the worker has had no prior relationship until the very moment at which they engage in responding behaviors.

Nonetheless, such ‘doing’ behaviors are compassionate behaviors, and if/when I would ask workers how they viewed their activities, they described them as compassionate responding as well. In other words, in some of these situations, recognizing and/or relating as conceptualized and theorized in the past compassion process conversations, were either not apparent, entirely missing, or emerging. Compassionate communication did not necessitate all three components to be present, unfold, or interact according to current conceptions. In most situations, workers felt that when they were responding, they were engaging in compassion. They did not feel differently about what they were doing, nor its significance or importance, if recognizing and/or relating were not present, or if they emerged at a later time. Recognizing and relating seemed to be the icing on the cake—that which made the compassion process richer and sweeter.

Hence, when all these factors are taken together, I believe a better way to understand compassion is to think of responding as the heart of compassion—recognizing and relating fill and complete the compassionate heart. In figure 8.1, I offer the following model and visual representation of compassion.

Figure 8.1: The Compassionate Heart



It is most important to understand the significance of the *heart* itself to my conceptualization and visualization of compassion. Metaphorically, the heart is thought of as the center of emotion (Tracy, Lutgen-Sandvik & Alberts, 2006). From Hochschild’s (1983) groundbreaking book on emotional labor, *The Managed Heart*, to references to the heart in everyday vernacular—when we are sad, our hearts break, when our feelings are genuine, they are heartfelt—we almost can’t even think about emotions without thinking about our hearts. When it comes to my data, the heart figures prominently in my interview transcripts and hospice workers narratives. Just a few examples from the hundreds of pages of transcripts are: “Patients get wrapped in your heart” (Leah), “The heart is an emotional muscle and hospice is all about the heart” (Sarah), “I communicate from my heart to their soul” (David), “She wears her heart on her sleeve” (Faith), and “Compassion is in your heart, not your head” (Dianne). Clearly, literally and figuratively, the heart *is* at the heart of compassion. The compassionate heart model is significant for a number of other reasons as well.

First, this model accurately speaks to and reflects hospice ideology overall and hospice workers specifically. As I have shown, hospice workers clearly view their work as a holistic endeavor, not linear, processual, or ‘pronged.’ Additionally, this visualization directly answers Sarah Tracy’s (2009) call for scholars to move away from the ‘box and arrow’ diagrams that currently punctuate much of the organizational research and scholarship. Furthermore, although the literature is thin, I can find support for a reconceptualized model of compassion in earlier discussions of compassion.

When reviewing previous studies of organizational compassion, I am assured that there is a clearly room to reconceptualize the way in which compassionate communication has been theorized. For example, despite the fact that they posit a linear three-pronged model of organizational compassion, Kanov et al., acknowledge that each sub-process is more interrelated than independently occurring. They state:

> Although examining the three subprocesses independently of one other allows for a clearer understanding of each of them, in reality, these

> collective processes are highly interconnected. Different processes often take place simultaneously in a set of organizational members, and any one process may feed into another (p. 821).

This statement implies not only interrelatedness, but that the processes can occur in any order, thereby acknowledging that recognizing, relating and responding may not be sequential after all. And in another study, Stephanie O'Donohoe and Darach Turley (2006) addressed the emotional labor and compassion experienced by workers at an Irish newspaper's *In Memoriam* desk when they encounter bereaved consumers. O'Donohoe and Turley's primary focus is in explicating and applying Frost et al's (2005) three organizational lens' of compassion, and not specifically Kanov *et al*'s three sub-processes. Yet, they do address noticing, feeling, and responding in one section of the article, and there was evidence indicating that the three sub-processes were either not sequential or not present (see the narratives of Maeve, p. 1439 and Lisa, p. 1440 for examples).

It is Katherine Miller's (2007) human service workers research, the largest and most clearly focused study of compassionate communication utilizing and extending Kanov et al's model, which clearly evidences the way in which my model of compassion could be especially valuable. Before further discussing Miller's research, let me clarify two things. First, it is important to note Miller makes clear that Kanov's model is only a starting point for discussing compassion in organizations, and not the only or end model of compassion. She states of the Kanov model:

> This relatively simple model of compassion—with its subprocesses of noticing, feeling, and responding—provides a helpful initial framework for exploring the nature of compassionate communication in the workplace. Using this framework as a starting point, it will be possible to describe more fully how compassion is experienced by human service workers, to consider ways in which communication enacts compassion in interaction with clients, and to understand more fully the outcomes of compassionate communication for those involved in emotion work (p. 228).

This is only one of a number of references to the Kanov model as being the starting point for further research and writing. Secondly, I do not intend to reinterpret Miller's data, only to discuss places in which my findings overlap with hers. I believe that Miller's research provides a substantial and noteworthy foundation that communication scholars can further build upon. That said, I will provide a few examples from Miller's research where there is evidence that responding could be seen as the umbrella component of the compassion model as I suggest in my model above.

First, in discussing processes of noticing, Miller argues that listening is a key communicative skill that her respondents depend upon in order to notice another's need for compassion. One of Miller's respondents (R#6) stated, "The more I'm listening, the more I'm doing compassion" (p. 231). This remark suggests that, at least for this individual, listening/noticing is the communicative action, the 'doing' response. With regard to connecting, one of Miller's respondents (R#9) indicated that there were situations in which she had a hard time connecting, or failed to connect. Another (R#5) talked about engaging in the response in hopes establishing a connection (p. 232), and a third respondent (R#13) talked about the discomfort she felt in mid-response when a client's emotional state changed or varied (p. 233)—all of which further elucidates the non-linear nature of compassion.

Lastly, when reporting the data pertaining to responding itself, Miller states:

> Several interviewees saw the response as the most important part of compassion, For instance, a family practice physician (R#18) said, "Empathy is too disconnected. You're not human if you don't pour some of you into your patients." In other words, it is not compassion if you do not respond (p. 233).

Miller's conclusion—that it is not compassion without a response—speaks to the way in which my model of compassion, which sees the response as the heart of compassion, helps elucidate her findings.

To summarize, current scholarly research on organizational compassion provide an important, valuable, or base understanding of compassion. My study contributes and extends current conceptualizions, illustrating the worth of discussing not only how we think about compassion in a theoretical sense, but also how a rearticulation of the concept might better serve us in practice. I will discuss the primary contributions of this study in the next section before moving on to address this study's limitations and future research recommendations.

Practical Implications

Given the very recent introduction of compassion as a theoretical concept and an area of academic research, the overall findings and theoretical contributions of this study, and the importance of hospice to an aging population, this dissertation should rightly include implications for practice. This study carries implications for the ways in which we think about and train hospice workers. Specifically, this study suggest that if responding is the overarching or core component of compassion, then it may be possible, through training, to engender and foster compassionate communication by focusing on and highlighting responding behaviors.

As was evidenced in this study, there were many instances when workers' response came first, and subsequently led to their recognizing and relating. This finding contradicts what many believe is a necessary, global *trait* for hospice workers to possess (compassion). It was a widely held belief within the hospice organizations where I conducted my research that when looking for, recruiting, and hiring workers, the organization needed to find 'compassionate' people. It may be that compassion is, or can be, a *state*, and that organizations can we create compassionate workers. One fieldnote I scribbled and now have prominently displayed on the front of my dissertation note-taking folder convinces me this is clearly worth consideration. When I was doing fieldwork at Hill House one day, a nurse adamantly stated that in order to work in hospice an individual must be compassionate. Later that day, when I went to the main office to set up my schedule for the following week, the intake social worker casually remarked that the beauty of hospice was that it created compassionate people. I marked these two seemingly contradictory comments with a smiley face and a double arrow (i.e., must be compassionate person ⇔ creates compassionate people ☺).

Organizations may be able to train individuals to be compassionate by stressing, or privileging, the response component of compassion. For example, if hospice organizations promoted a “do or try anything” ethos, they may be able to create compassionate workers. While hospice workers are afforded more autonomy in their job than other healthcare specialties, they do nonetheless follow a traditional organizational model in which some members have power and control over other members. If workers at all levels were encouraged to ‘think outside the box’ with regard to responding to their clients, positive feelings about themselves and their jobs may ultimately result in the creation of a compassionate worker. Understandably, a do or try anything stance may only, at this time, be an option for hospice organizations. In hospice, all expected client outcomes are the same—the client will die. Hence, there is little risk in trying anything. But we should not overlook the potential positive outcomes that result from empowering workers and making them feel as if they have personal control over job.

There are numerous benefits to be gained from empowering individuals as a means to create compassionate workers. Clearly, the primary beneficiary of compassionate workers would be the client. Additionally, however, workers and the organization would benefit. The literature tells us of the detrimental effects of occupations with high emotion demands, from the health and well-being of the worker, to high employee turnover for the organization. Yet, the fact that hospice seems to defy the organizational emotion work norm, suggests that compassion may be one factor that has contributed to its success.

Limitations and Future Directions

All research studies have limitations, this one included. But limitations also present opportunities, which is why I have chosen to address this study's limitations in the same section as future directions. In other words, some of the limitations I will discuss also point to future research possibilities.

The first limitation of this study results from the fact that compassion is such a new, emerging area of study. On one hand, this dynamic does present a tremendous opportunity that I personally am grateful and excited about. It may, however, also be seen as limiting in the fact that there is little previous research to serve as a foundation, particularly from within the communication disciple. Having the wisdom and expertise of your disciplinary scholars and peers upon which to draw, is imminently helpful and reassuring to an emerging scholar. A "blank canvas," as both positive organizational communication and compassion felt to me, may seem exciting. But for an emerging scholar, as I am, confronting the blank canvas can be overwhelming. I found myself second-guessing my initial observations and inclinations, wondering if my research questions were too broad, or were they not broad enough. On the one hand I wanted to push the envelop, yet on the other, I didn't want to push the envelop because I knew there likely would not be anyone there to back me up. Hence, in most cases, I took what I believed to be the middle ground—challenging traditional organizational worldviews about what and how to understand workplace theory and practice, i.e., incorporating positive and negative workplace discourses, yet adopting and adapting the frames of compassion theorized by the few scholars how have ventured into this area.

Another limitation of this study may be its broad scope in terms of job categories. In order to gather the data I felt necessary to undertake and complete this dissertation, I chose to incorporate the narratives, interviews and findings from my fieldwork that included four hospice job classifications—social workers, nurses, aides, and spiritual care providers. One of the reasons I opted for such a large scope is because of a limitation I encountered in my first study of hospice nurses. In that project, I found that given the workload and long, twelve-hour shifts they worked, their availability for interviews was extremely limited. Hence, when I began brainstorming this project, I understood and expected that I would encounter the same problem again if I were to only focus on one job classification. And given that my overarching goal was to uncover the way in which compassion is enacted and experienced in hospice overall, I clearly felt justified in the choosing such a wide variety of workers.

Yet, this broad scope resulted in less depth on any particular group's practice of compassion in hospice. It is possible that there are distinct and significant variations between job classifications. For example, a majority of the social workers I interviewed either directly addressed or subtly alluded to their belief that nurses and CNAs (as well as many clients) do not value them and/or the work they do. The reason for feeling like they are not valued, they state, is because the work they do is not physical work like the work of nurses and CNAs, but administrative and psychological instead. And although I did not ask any of the nurses or nursing assistants if they felt like the social workers were not working as hard as they were or if what they did was not valuable to the organization, none of them ever gave any indication of resentment or animosity toward the social workers.

Relatedly, because all my participants were aware that I was observing and interviewing all job categories is it possible their answers and/or behaviors were influenced by that knowledge. In other words, any one of the four job titles may have articulated their understanding of compassion differently if they believed that they were contributing and giving voice to their group specifically and not hospice overall. These limitations suggest one possibility for future research. It might be worthwhile to focus solely on social workers, nurses, CNAs or spiritual care providers in future examinations.

This study was also been limited by the fact that the two hospices where I did my research were for-profit hospices. Although the hospice “market” is almost evenly split between for-profit and nonprofit hospices, there is often a perception that one or the other type of hospice is better or worse in some way that the other. For example, one of the hospices where I conducted research, Desert Hospice, is the second largest hospice in the area, with the largest being a nonprofit. The nonprofit’s advertising campaign draws on its nonprofit status, implying that the nonprofit status translates into somehow better, more genuine care. I do not adhere to this belief in any way that a hospice’s profit status has any bearing on quality of care, or the way that any individual working for the organization understands or experiences compassion differently. However, the difference of compassion in profit versus non-profit is not a question I asked or addressed, and future research may fruitfully hospice workers at nonprofit agencies as well.

With regard to future research specifically, one area that presents an interesting and important possibility is in the area of gender. I recall from my original study of emotion management in hospice nurses that I found the men to be far more open to talking about the emotional dynamics of the job than the women, which I found to be intriguing and counterintuitive given much of the research. More recently, at one of the inpatient units where I conducted participant observation, Avenida Sur, there was one male CNA (Brian). Brian was an anomaly where CNA's are usually female, and men are far more likely to be employed as nurses, social workers or spiritual care providers. Brian was very popular with the patients, particularly the 'ladies' who loved his attention and engaging in banter. My fieldnotes from the days he worked are some of the richest, most colorful and clearly the most humorous of all. This data alone leads me to believe that Brian's experiences of compassion may be quite different from the women's. Thus, coupled with my previous experience, I believe it might be worthwhile to investigate in gender differences and compassion in hospice workers—an area that is clearly under-investigated.

And finally, issues pertaining to the claims of authenticity that hospice workers discuss warrant further investigation. As illustrated in their relating practice a number of workers intimated the emotions they experienced were genuine, and they never had to fake the way they were feeling. For example nurse

Irene told me that more than any other job she has ever held, she feels that in hospice she can truly be her ‘authentic’ self, stating, “I never have to fake the way I feel.” Yet, there is an important distinction worth noting here.

While Irene and other workers stated that they were free to experience and display emotion on the job, the stories and experiences they most often told were framed as ‘positive’ emotional stories. That is, even if they were crying with someone or in response to a situation, it was a positive or emotionally appropriate response to the person or situation. That is not the case in most other healthcare settings where emotional displays, particularly crying, may be viewed as unprofessional (Li & Arber, 2006; Lerner, 2008). Indeed, the organizational appropriateness for showing tearful emotion clearly showcases one of the qualitative differences between curative healthcare and palliative healthcare.

In contrast, absent from most of my participants stories were descriptions of negative, perceptually inappropriate, or unwanted “deviant” emotions—at least not as they pertain to clients. Many of the emotions they framed as “negative” were reserved for organizational aspects, such as workload, etc. (some of which I discussed in the section on barriers to recognizing in chapter four). I found an example of this dynamic at work in a story that social worker Leah told me. She had worked with a client—Mr. Rowland, a man in his early 40’s with a wife and two young children—who had endured a long and protracted illness that left him in a lot of emotional and physical pain. Over the months that Mr. Rowland was receiving hospice care, she became very close to him and his family. As Leah recalled, “There were times when the whole family was just crying, and I cried with them. As long as the focus isn't on you, that comforts them." When she arrived at the unit one morning, she found that Mr. Rowland was actively dying and, needless to say, she wanted to spend his final hours with him and his family. But the staff told her she was needed elsewhere. Another patient had died during the night and the man's partner had thrown herself on his body and wouldn't get off. The woman was despondent and uncooperative. The staff needed Leah to intervene and help the woman who was splayed across the dead man's body. She ended up spending four hours with the woman, medicating and stabilizing her. By that time, Mr. Rowland had died and the morgue had come and removed his body. Leah continued

> I was devastated! I went home and cried all night because I didn't have closure. I mean, the staff knew how close I was to Mr. Rowland. They should have called me in sooner. I would have come in no matter what time it was. And I don't think I was the only person that could have helped the woman in the other room. All she really needed was some meds and a little time. But then I realized that there was a reason why I was meant not to go into Mr. Rowland's room…because I loved his family so much! I probably wouldn't have been able to handle my emotions. Maybe, you know, maybe God was protecting me that morning. Maybe Mr. Rowland just needed to be with his family, and I know he would have wanted me be with the other woman if she needed me. But there was something, there was some reason for not going in that morning.

Leah's story highlights the way in which workers framed and/or reframed experiences (or potential experiences), in positive ways.

Hospice workers engage in a great deal of sensemaking (Miller, Joseph & Apker, 2000; Weick, 1995) in which they reframe situations in positive manners. Perhaps no experience calls for more sensemaking than illness, death, and dying, regardless of which side of the equation you are on. In Leah's case, crying with Mr. Rowland's family is alternately "comforting" in one situation, and potentially dangerous in another. Leah made sense of the situation by determining that it was divine intervention that prevented the enactment of behavior that would have resulted in negative, inappropriate or unwanted emotions. In this way, she framed this client interaction and experience positively. In contrast, the only people worthy of scorn were her co-workers, who failed to call her, handle the uncooperative woman, etc.

In short, it was interesting and noteworthy how hospice workers claimed the authenticity and lack of faking involved in their job. However, their positive retroactive sensemaking suggests that hospice workers engage in more emotion management than they admit, and claims of authenticity may have their limitations. It may be that, for some workers, the act of (re)framing client interactions in a positive way is necessary for them to be able to engage in compassion work.

I believe that contrary to what some workers say they, at least sometimes, are engaging in more emotion management than they care to admit. But this begs the question of whether compassion, or the various processes of compassion, are or even need to be, authentic in some way. In other words, is it still compassion if it is only a performance of compassion? Does it matter? The literature on emotional labor has long reported that individuals who engage in emotion management risk occupational stress and burnout (Hochschild, 1979, 1983; Tracy, 2009). But, can we assume that the terms and concepts of emotion and compassion are interchangeable, or are each unique and different in some way. Hospice workers continue to report high rates of job satisfaction (Brenner, 1997; Qaseem, Shea, Connor & Casarett, 2007), which leads us to question whether faking *compassion* is, in fact, detrimental to well being, as some of the literature on faking *emotion* would say. Or, whether there even is an experience of "compassion management" that workers' engage in. Or perhaps, it may suggest that like Tracy & Tracy's (1998) findings on 911 call-takers, there exists other potentially influential mediating factors that offset the negative impact of compassion management. In any case, authenticity of compassion is an idea that seems primed for further research, particularly from communication scholars.

Conclusion

I begin my summary and conclusion with the words and recommendation of organizational scholar and cancer survivor Peter J. Frost (1999):

> I think there is a whole rich, vibrant, exciting world of understanding about organizational life that is waiting to be engaged, and one of the keys to this engagement is compassion. Compassion counts as a connection to the human spirit and to the human condition. In organizations there is suffering and pain, as there is joy and fulfillment. There is a need for dignity and self-respect in these settings, arid to the extent that our

> theories, models, and practices ignore these dimensions, so do they distort our understanding of life in these enterprises. Looking at organizations through the compassion lens brings this “disappeared” world into focus (p. 131).

Far from being a mere turn of the cheek—from negative to positive—compassion is clearly a complex and dynamic component of organizational life. As a newly emerging area of academic research within communication studies, this dissertation responds to Frost’s call to look at organizations through a compassion lens. And perhaps no organizational world is as “disappeared” as the world of hospice, death and dying.

This chapter summarized my research findings, proposed a reconceptualized model of compassion, provided practical implications, theoretical implications and recommendations for future research. This dissertation opened the door to future scholars and researchers interested in expanding and contributing to the discourse on positive organizational communication, emotional labor, and hospice. Personally, this project provided me the opportunity to engage in research I am truly passionate about and interact with people I truly love—those individuals who are both living and dying.

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APPENDIX A

INTERVIEW PARTICIPANTS

Grouped by occupation

Pseudonym	Sex	Occupation	Years in Hospice	Years w/current agency
Carrie	F	Nurse	2	1
Charlene	F	Nurse	16	10
Diane	F	Nurse	7	7
Hannah	F	Nurse	6	6
Irene	F	Nurse	2	2
Jane	F	Nurse	3	3
Janet	F	Nurse	2	2
Lisa	F	Nurse	12	12
Mary	F	Nurse	5	5
Frank	M	Nurse	7	3
Daniel	M	Nurse/Spiritual Care	10	10
Debra	F	Nursing Assistant	2	2
Faith	F	Nursing Assistant	1.5	1.5
Katie	F	Nursing Assistant	7	5
Peggy	F	Nursing Assistant	12	9
Summer	F	Nursing Assistant	3.5	3.5
Susan	F	Nursing Assistant	1	1
Annie	F	Social Worker	23	11
Beth	F	Social Worker	19	.25
Leah	F	Social Worker	6	2
Sarah	F	Social Worker	10	6
Brian	M	Social Worker	18	5
James	M	Social Worker	.5	.5
John	M	Social Worker	4	4
Marcy	F	Spiritual Care	2	2
David	M	Spiritual Care	10	10
Mean/Median			15.66 / 6	10.79 / 3.75

APPENDIX B

INTERVIEW GUIDE

Opening Questions

1. What is your job title?
   - A. What does that entail/What is the scope of your job?

2. How long have you done this work?
   - A. How long have you been with this organization?

3. How did you come to choose hospice work?
   - A. Did you get any type of specialized training?

General Questions to elicit stories of well-being, compassion, fulfillment and/or fatigue

4. Can you tell me about a time when do you felt especially appreciated by your patient/client?
   - A. A time when you felt especially appreciated by a co-worker(s) or your organization?

5. Can you tell me about a time when you felt misunderstood or unappreciated by your client/patient?
   - A. By co-workers or the organization?

6. Can you tell me about a time when you had a ‘bad day’?
   - A. How did/do you come back or recover from a bad day?

7. Have you ever felt detached from a patient/client? If so, can you tell me about it?

8. Can you tell me about a time when you didn’t know what to do?

9. How do you know if someone is suffering?

10. With regards to your work, what energizes you?

11. With regards to your work, what depletes you?

12. What would your ideal day at work be like?

13. What does compassion mean to you?
    - A. How do you convey compassion to your patients?

14. In all the time you have been involved in hospice work, is there one particular incident or patient that stands out in your mind for any reason that you can tell me about?

15. Do you feel differently about your job today than when you first started? If so, how?
    A. Were there any particular ‘turning points’ along the way that may have contributed to this?
    B. Would your family or friends say that you have changed in any way since starting hospice work? How?

16. How long do you think you will stay in this line of work? Why?
    A. Are you now, or have you in the past, considered leaving hospice work? If so, why?

17. What qualities do you think someone wanting to work in hospice should possess?

18. What would you tell someone considering hospice work?

19. Most research would suggest that hospice workers should be burned out, yet many studies have found that they are not burned out, and in fact report very high job satisfaction compared to other workers in other health care settings. In general, do you think most hospice workers are burned out? If so, why? If not, why do you think they are not?

Closing Question

20. Is there anything else you would like to tell me that we haven’t already talked about?

APPENDIX C

INFORMED CONSENT FORM

Dear Study Participant,

Much of the research that has taken place within organizational health communication has been purely prescriptive in nature. That is, researchers were concerned with uncovering what was wrong within organizational life, and then proposing solutions to those problems. But the study of organizations and organizational life has recently seen a shift in focus; Researchers are now looking at organizations more holistically and are interested in uncovering all aspects of organizational life—positive, negative, and even neutral. Compassion is the larger focus of this study as it is inherently communicative and carries both rewards and demands.

I am a researcher and PhD Candidate in the Hugh Downs School of Human Communication at Arizona State University under the direction of Dr. Sarah Tracy (sarah.tracy@asu.edu). I am requesting your participation in an interview that asks about the experiences of individuals who work in hospice and are involved in direct patient care. I am conducting this research to better understand how (or if) compassion and emotion impact hospice workers sense of well-being.

Interviews will be digitally audio taped and then transcribed, and will last 30-60 minutes. For archival purposes, the audio version and the transcription of your interview will be kept indefinitely in a locked office of the researcher. I may also use as data the information you provided via email interactions. Written accounts of the research may be published, but your name will not be used. All identifying information, including names of organizations and other staff members, will be altered in published materials.

Risks of participation should be minimal and would largely focus on feelings associated with reliving some emotional experiences. Possible benefits to participation would come from the knowledge that you were contributing not only to the current body of research on hospice workers, but to a new area of health communication research as well.

Your participation in this study is voluntary. If you choose not to participate, or withdraw from the study, you are absolutely free to do so. If you have any further questions concerning this research study, please call me at (602) 418-6672, or email me at dway@asu.edu.

Sincerely,

Debbie Way, M.A.
Hugh Downs School of Human Communication