THE COMPETING DISCOURSES OF CARE AT THE END OF LIFE

by

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The Competing Discourses of Care at the End of Life

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Abstract

This project details the nature of discourse and its consequences surrounding end of life care inside an emergency department and hospice. Detailing the way discourses organize meaning illustrates relationships between providers’ language use and care practices. At both sites, providers struggle to manage the tension of providing humanistic care in settings that are inherently routine and regulated. In this project, providers’ work practices transform to deal with this tension.

As providers attempt to rehumanize care practices through language use, they ultimately tame death. Taming death allows providers to deal with the wildness and complexity of it but at the same time, taming death also tames and suppresses important conflicts and discussions from taking place. Even more, in taming death, meanings surrounding the culture of death became reproduced and naturalized thereby concealing them from critical engagement. Consequently, certain choices about how death should be handled and understood take priority over other choices and meanings that remain invisible or unspoken. Reopening choice and the way meaning around end of life is produced adds to current literature in several ways.

The study contributes to theory and practice by (a) conceptualizing the everyday ways in which work practices and language influence end of life care, (b) detailing the role organizing processes play in the construction and organization of medical care around end of life, and (c) showing how reopening choice regarding meaning production
is needed for education, policy, and practice.
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Chapter 1:
Dying in the 21st Century

Almost a third of the money spent by Medicare—about $66.8 billion a year—goes to chronically ill patients in the last two years on life (Newsweek, 2009). Medicare, the federal health insurance program insuring 47 million elderly and disabled Americans, helps to pay for hospital and physician visits, prescription drugs, and other acute and post-acute services (Medicare Spending Fact Sheet, 2010).

More than 90 million Americans live with at least one chronic illness, and seven out of ten Americans die from chronic disease (Dartmouth Atlas, 2009). As chronic disease progresses, the amount of care delivered and the costs associated with this care increase dramatically. Patients with chronic illness in their last two years of life, for example, account for about 32% of total Medicare spending, with much of it going toward physician and hospital fees associated with repeated hospitalizations (Medicare Part A and Part B).

In 2000, thirty-five million American people were sixty-five and older. In fiscal year 2007, $2.2 trillion dollars were spent on healthcare and Medicare spending is expected to increase from $426 in 2007 to $844 billion in 2017 (Medicare Spending). Even more, the Congressional Budget Office predicts that the cost of long-term care will reach $207 billion in 2020 and $346 billion in 2040 (Congressional Budget Office, 1999).

Recent debates around end of life issues have been framed and halted with talks about health care reform. Politicians have fueled the debate with their inflated talk of “mandatory death panels” and “killing off our old people” by pushing them into hospice care. In addition to recent health care reform debates and economic policy issues, a larger
and more general issue exists: As human beings, we are undeniably mortal. But it’s not so straightforward. Indeed, the reminder that we are mortal beings has been hammered, slapped and stabbed into my mind, my heart, my body and my soul over the life course of this project.

Life is fragile and more often that not, life is not fair. People die – young, old and not so old – every minute of every day. We die cold and we die warm. We also die immediately, unexpected, and perhaps over an extended period of time. We die with family and friends around and we also die alone, something I am afraid of. Often, we are not sure how we want to die or have any idea how others wish to die. And sometimes, we talk more about a person’s life when we realize they’re dying, than about their life when they are living.

Even more, we tread deeply in language that both constrains and enables our understanding of life and death. For example, why do we say people have gone “to a better place” or “it’s a blessing they have gone to be with God” after someone dies? And why do we suffer asking, “why did they take him so young” or “this is not fair for her to die this way” and “why can’t we just figure out a cure so this doesn’t happen again?” These words and discourses keep me up at night because no matter how sick or ill someone is, we are never ready to let someone go, or let go of ourselves.

Words do things for us: they make us feel, they make us think, they help us reason, they take us places, they hurt us, and they also heal us. For these reasons, there is tremendous struggle around meaning, interpretation, and communication at the end of life. We struggle to make sense of the dying process. We struggle to understand how we should live in order to have a peaceful death. We struggle with what people say and what
people hear around the dying process. We struggle interpreting the significant costs and spending associated with the end of life. We struggle with interpreting what a hospital and hospice is like, and what it should be like. We struggle interpreting the significance of our life as well as the life of others. We struggle making decisions about how to live, and of course, how to die. We struggle making decisions about what kind of care we should receive, or what kind of care we can afford or have access to.

We also struggle communicating with people who are dying. What words do we have available to us? What words help in these situations? What words hurt us in these situations? Are my doctors talking to each other to coordinate my care? Are my patients listening to my care plan? Will my insurance cover this treatment? And we struggle with saying too much or not being able to say enough to someone who is dying. Therefore, end of life is a subject that is significant to all of us because the decisions we make – and the decisions made for us – have significant social, economic, political, physical, and emotional costs and losses.

In order to understand how communication is critical to understanding end of life, I have chosen two sites–an emergency department and hospice. I will introduce the sites throughout the pages so that you may begin to get a feeling, as I did, for what they are like. You will hear from the providers themselves through narratives and actual interviews. But it is important to note that what you hear will be a representation of what they actually said, since you in fact were not there and therefore, it is unfair for me to believe that you will hear them in the same way I have. In addition to hearing providers, you will also hear my own voice describe what it felt like being there as a way to orient yourself to life in a hospital and life in a hospice. Beginning to feel what it is like in these
places will give you an understanding of the complexity of these spaces, the vocabularies used in these places, the events that take place. More, it will give you a feeling for what it is like to work in these places, and a feeling for what it is like to be a patient in these places. Because after all, the way we feel is inherently connected to the language we use and to the many ways language uses us. Essentially, the way we talk about life and death has consequences and opportunities for the way we feel, think, and act. That said, you will hear two voices throughout these project: one voice trying to understand what is going on and another illustrating the consequences of talk in both of these places.

Just as important, in these sites, I was an incoherent person constantly being true to what I was hearing and also being true to the craziness I was feeling about life and death. But it is in the emotional and incoherent moments where I understood the most and I gained tremendous insight. My feelings of craziness and incoherence in these sites give a detailed sense of what often gets hidden behind protocols, algorithms, and routines in order to control the uncomfortable rhythms that beat within their domains.

In this dissertation, I will provide a descriptive picture of the communicative norms, strategies, and realities that I have observed within the context of an emergency department and hospice over the past two years. Behind the glass doors and windows of both sites and hidden mostly from public view are the workers, providers, families and patients who bear witness to the pain and suffering of death as well as the joy and hope of life. And behind these glass doors, I have met intelligent, compassionate, and humble people. Providers who endlessly inflict pain in the name of healing, are the bearers of hope, and the messengers of death are extremely emotional roles when embraced at these places (Hirschmann, 2000). Providers who work every day in the face of life and death
speak through voices, interactions, norms, stories, realities and experiences that are rarely questioned and deeply misunderstood by many of us on the outside. Together, they provide an important picture of what it means to live and die in the 21st century and how we deal with the challenges and opportunities of coordinating care around the end of life.

My purpose is to understand these stories about life and death and to give the readers a chance to learn as I did, listening to patients, providers, and family members speak for themselves. Additionally, I focus on ways of talking to expose the ways in which language produces experiences for care around the end of life. Even more, I focus on language to expose how implicit values are shaping choices and decisions around end of life.

This project provides no solutions, answers or panacea to dying or living with illness. Rather, my goal is twofold. First, I will use insights from different positions to build an intuitive way of talking about communication that enables the reader to rethink the processes of interacting with others around end of life. Second, I will attend to the subtle processes of meaning and decision production in order to disrupt common ways of talking and interacting around end of life thereby bringing contestation to a set of practices that are both constraining and enabling patients, provider, and families ability to talk differently, and have some choice in the meanings surrounding life and death. Because this project is proposed more as a window on clinical life than an overview of the medical field, it is written in a way it should be accessible to families, patients, providers, and academics.
The Changing Medical Landscape Concerning End of Life

Rapid changes in the organization of U.S. medical care and technology have altered the communicative contexts in which patients, families, and providers make their decisions and coordinate care around end of life care. Discourses of death and dying have consequences for how individuals interact and make decisions in everyday life (Seale, 1998). Discourses also provide and organize a variety of narratives and discursive resources to dying and bereaved people to interpret their situations as well as for those providing care. That is, what is possible to know, to do, and to be in clinical settings as a patient, a family member and a provider within a changing medical environment.

This study examines how clinical settings such as an emergency department and hospice both encourage and stifle discourses about what it means to live and die and it examines the ways in which these discourses intersect with the unique circumstances of an individual’s life and health. Moreover, this project focuses on how we as a society engage in language and discourses designed to transform an orientation towards death into one that embraces life. My hope is to understand how delicately balanced discourses are organized in managing life both in terms of quantity and quality of days.

The language of an emergency department and hospice often is considered to involve two voices – emergency and hospice medicine. Even so, the claim there are only “two” discourses, like “clinical” and “curative” is highly problematic because embedded in care settings is a conglomeration of discourses about relieving pain and the inherent disparity of saving and ending a life. This opposition, however, is largely accepted and rarely interrogated. Even more, what is rarely interrogated is the very complexity of language and human interaction. Therefore, in this study I move from our everyday
normative and rational impressions of how to talk, or how others should talk around end of life, to an in depth look at the complexity of talk and the unique ways language is used around end of life.

In what follows, two medical providers share their accounts of working in end of life care in contemporary times. This is the first move—or invitation—for you to step in and begin to get a feel for these places. The narratives are cleaned up to be read as stories, but the words belong to the providers. The words not in italics are my verbatim interview questions. After each narrative, I include my own voice or reflection describing the sites when I first arrived in order to share my own attitudes and assumptions from the outset and how they evolve over time. Narratives like the ones introduced here, taken with others that will be dropped in to the following chapters, should be read as stories so you, too, can “step in” and begin to feel like you are at these sites.

Gerry is a nurse practitioner at hospice. She has reddish shoulder-length hair parted on the side and rectangle-shaped wire glasses. She has soft wrinkles around her eyes and a very warm, soothing voice. She smiles a lot and wears a huge green hospice lanyard around her neck with a fistful of keys. She was holding her flip cell phone and a stack of papers when we met. We sat at a small fake-wood coffee table in the hospice kitchen. Three other tables were filled with patients, visitors, and staff who hummed in white noise. The ice machine was grinding in front of me and metal trays of plates and silverware were stacked on a dolly while another woman removed each tray and hosed off the plates placing them on another metal tray to be dried. Behind Gerry was a five-foot wide fish tank with artificial coral and several colorful fish swimming in circles as the filter bubbled and gurgled. Gerry was drinking a hot Chai tea in a white mug she had
taken from the coffee machine in the kitchen and the artificial scents of machine Chai and black Folger’s coffee like you inhale at any diner was all I could smell. I had a glass of water in a clear plastic cup with no ice. In the following narrative, she described the challenges and gratifications of her work in general and the language of hospice in particular.

What’s a bad day here? *Well a bad day is when I can’t help somebody in the sense that they don’t seem to understand what I am saying or maybe the team isn’t able to communicate effectively – I mean that is really one of the key challenges with our role is what we say and what people hear. And if we are speaking different languages, which can often happen at the end of life, then poor communication is going to make for a really bad day. And it happens in all different shapes and sizes. Each situation is going to be different but if you have a day where you are just not able to communicate openly with another person, it’s going to make for a really bad day.*

What do you mean by different languages? *Could be a cultural difference. Could be just a knowledge deficit about their disease process. It could be in the form of – maybe they are just in a different place of their illness, their journey – they might have an expectation that is not aligned with hospice necessarily. Not everyone comes to hospice knowing what hospice is or understanding what hospice is, or being ready for hospice. So we’re not here, I’m not here to make them ready but to meet them where they’re at and to see how I can help them best. And that may be staying here on hospice or it may be finding what’s in line with their particular goals and values.*

What’s important for this kind of work? *First and foremost, you are a human being so don’t forget you are a human being! You have to be genuine. I would say listen*
to other people as much as you can and when you find that you are not able to interact with people anymore whether it is on that given day or that you have to take care of yourself or you’re never going to be able to take care of other people. So care for yourself, be genuine.

You have to be really empathetic. You have to be very compassionate. You absolutely have to have a good heart, which probably encompasses all of the above. I would say the primary characteristic that you really need is to be an empathetic person. But at the same time you have to realize that this is the patient’s and family’s experience and not your experience. So that they – the patient and the family – are essentially the ones that are going through this and you are trying to guide them.

Are there any barriers that get in the way trying to guide patients and families? Yes, in fact, the day-to-day nonsense I like to call it, just the interruptions, the flow of events, and the work environment. Essentially, when I talk or meet with a patient and the family, I try to immerse myself in that experience and really close everything else out and not be thinking about what else I could be doing whether it’s with another patient or whether it is something personal, to really give 100% when I am with that patient.

Because being a nurse to me is something really special. It is something that is very personal, it’s just a very unique relationship that you have with another individual that you aren’t always able to share in other locations or professions. And it’s something that, being a nurse to me it’s more about, it’s not just the medical piece or the health piece – it’s really relating to that person in a way where they feel open enough to disclose things that are very personal and private issues. And you have to earn their
trust, you have to earn their relationship, you have to know just because I am a nurse doesn’t mean you have to tell me everything about you.

Are there specific things that you do with patients? Yes, of course. I try to just get to know the person. It’s hard because there is a blur between personal and professional but I just try and engage the individual just talking with them, not just coming in and just focusing on the issue at hand. I mean if I come in and say how is your breathing today? If that is going to be the extent of my relationship with a person, then that is probably how they are going to disclose things to me, reveal things to me and that’s all our relationship is going to be. For hospice, where we all wear multiple hats and even though I assume the medical provider/nursing piece of their care, I can’t shut them down if they want to talk about something else because that is not what it is all about. So I essentially just try and get to know that person, try to get to know what they are comfortable revealing to me and go from there.

Hospice care is difficult and people often don’t have a good sense of what it is. How come? Well, there is a real interest coupled with fear. It’s a real conversation stopper at times. There are a lot of people that just say, “ooohhh.” My family and friends will still ask me but there is still kind of a veil that comes over them when they talk with me about how are things at hospice, their voice changes and it’s serious stuff and I realize in conversation with them how open I have become to talking about dying and the end of life and how comfortable I am on a professional level with discussing dying and end of life issues. Do they understand what you really do? A lot of times, for example, my family and friends will ask me exactly what I do and they have an accurate impression. My brother, he doesn’t live in town and he has known that I have worked as
a nurse practitioner at hospice and he kind of skirts the issue a little bit. You know I don’t think he fully understands what I do.

Why do you think this problem exists? *I think a lot of it is very emotionally charged.* You know each and every one of else has known someone who has died and for most people it kind of elicits a painful emotion, probably a mixture of feelings. And so when people talk about dying, especially if they don’t have the professional perspective, it becomes a very personal event and it’s kind of; they may be respectful, they may feel a lot of gratitude towards hospice professionals either in the past but for a lot of people it really isn’t a pleasant experience so it is something that makes them very emotional and not necessarily in a good way.

My reflective experience: The smell of bedsores and Clorox burn my eyes and penetrate the back of my throat as I enter hospice. The hall is wide, big enough for two wheelchairs. Walking on the gray carpet by each room, by the artificial flower arrangement over the patient’s name and room number, I look in each room hesitantly before turning my head quickly when making eye contact. Why did I catch many of their eyes so frequently? Why did I feel so much resistance looking at these patients, these people, and these individuals? How could I walk by without looking at them? Was I contributing to their own objective and stigmatized position of being a hospice patient?

Attempting to understand end of life communication, why was it so hard to look, feel, hear, and smell what interests me so much? Maybe the only thing these patients want is for someone not to think something is wrong with them, that they can’t be looked at, touched, or talked to? Maybe talking and listening to them was exactly what we both needed? What if that was me? Or my family and someone walked by or jerked their head
so suddenly when they caught my eye during a time of great uncertainty in one’s life?

Transitioning through a system that deals with patients and their identities by bed numbers, scores and results, how was I enacting a new form of identity? What would it be like to die if people were essentially trained to value dying instead of being unimpressed by the fragility of life itself.

Now, begin to step in and get a feeling for the emergency department as Susan, an emergency physician shares her experiences. We met at her house in Denver and sat in the living room that looks out on a quaint city street with dog walkers and joggers. She has short brown hair, freckles, and large hazel eyes with flashes of green tint. She smiled with bright white teeth that lit up her face. She was wearing blue scrubs and a gray half-zip sweater when we met because she had just arrived from a PT appointment after the night shift at the emergency department. When she sat down on the sofa, one of her yellow labs jumped on her lap and the other found a spot on her foot. She was eating a Stoneyfield fruit yogurt shortly into the interview, feeding herself, and then offering a lick off the spoon to both dogs. Here she describes the challenges and gratifications of her work in general and the language of emergency medicine in particular.

*It’s like a job like everyone else’s job. You know you pack your lunch, hoping you get a few minutes to eat in peace. I mean, it’s just weird, you know sometimes a patient will die and a minute later we are ordering pizza and it’s not that we have disregard for that person’s life, it’s that – that’s our job and it’s no different from the guy who is a car mechanic where it is tragic for the car owner whose transmission fell out, who can’t afford to replace it and that car is dead. Yeah, you say, but we’re talking about a life. I get that but everything is still a job and you don’t want us – I mean what are you going to
do, someone dies in the ER and everyone has to go home because they are so emotionally
distraught so we have to bring in a whole new crew? That is a hard thing for people to
get. It’s not that we are not compassionate – we’ve been doing it for 20 years and our job
goes on. As soon as you finish with this one person who died and console their family,
now you are 15 people behind and they are all mad as hell at you.

What makes for a good day at work? I think the personalities in the ER – different
nurses, and other docs you are working with – is definitely one of the bigger variables. If
you’ve got the right mix, every one has good energy, it’s funny, sarcastic, playful and we
can diffuse a patient’s energy with each other. The patients that wear us down are the
patients that are demanding, have ridiculous expectations, like I have had this for fifteen
years and I have seen 10 specialists and I am here Friday night at 10 pm and I expect
you to have an answer to why this is going on. That can be absurd and sometimes you
can let it roll off you but sometimes patients are so in your face and make you in your
weak moments really defensive and engage that behavior and that makes for a bad shift.

And then there are other things in the mix that make for a bad shift – last night it
was a bad shift because there were a lot of patients that had a lot of sad diagnoses, like
one woman came in, had breast cancer 15 years ago, she had bilateral mastectomies,
they didn’t recommend chemo and radiation, they said it was not called for it was such a
small tumor and she comes in with a complaint of a herniated disc kind of symptoms and
has enough neurological symptoms that I did an MRI because she had lost her reflex, she
had lost some bladder control, and sometimes that means you have to do something
surgical. Got an MRI and she had boney metastases throughout…and you know it was
like taking all the wind out of her sail and I think she thought it was never something
she’d ever worry about that came back …you know that is hard, it’s hard to give somebody that diagnoses, it’s hard to feel like in the ER you’re doing anything but dumping all this horrible information on them saying, alright, why don’t you follow up with your doctor, we need the bed, there’s 15 more in the waiting room.

You know it’s like you can’t spend enough time with them – you know it’s not like they need you to spend more time with them that minute because they need some time to take it all in and sort it out, but the ER seems like a funny place to be handing out that info. So, bad diagnoses can wear us down because we are people too you know and we have our own illness and fears about getting illnesses or it might remind you of a friend you had that had something and it just sometimes gets really personal and it’s hard to keep up your defenses and it’s not to say that you are like a wall and impervious to all that is around you but I don’t know that people get that. At some level we have to have the wall up or we would be consumed by horrific diagnoses and sadness and other stuff we do.

Having to try and save someone’s life while family are wailing right next to you, is not an easy task. You have to somewhere put it aside and though you know it hurts – you’re trying to help somebody and I guess that is the hardest part that in medicine, at some point you have to figure out how to manage it and if you don’t find a way to let it out later it starts to make you a bitter, cynical, burned out doctor that takes it out on people and that is the end result that patients see and say what an ass that doc is, but they might not appreciate all the pain and suffering we’ve had to bear witness to that has taken it’s toll on us, even though we signed up for it. It still is hard and they don’t teach us how to manage that. And there are conferences and lectures on how to handle the
difficult patient or whatever but it is not really something we embrace. You know it’s not like, hey look what I am going to. It’s more you take it on because somewhere down the line you learn you’ve got to do these things to save yourself.

My reflective experience: Red phone rings as Kelly, a nurse, walks out of the break room. It rings a second time as she picks up the phone in her left hand while simultaneously opening the pen with her right hand that is attached to the dry erase board above the phone. “ER”, she states. And begins writing the symbol for female, 58 and then two other codes I didn’t recognize. “Ok, we’ll have a bed ready for her when she arrives,” she says and hangs up the phone.

Doc, eating Edamame and Rice Krispie treats swivels around, glances at the board and then around to me and says, “that’ll be a good one for you.”

Oh, shit, I think. How the hell could she know that much from those two simple codes on the white board? “Why?” I ask.

“She drowned and has no pulse,” she says.

I sigh again as three nurses make their way into bed 2 removing and changing lines, preparing IVs and activating monitors. Brent’s voice, a triage nurse, comes over the intercom saying, “ambulance arrival bed 2, ambulance arrival bed 2.” I am standing near Doc’s computer as the stretcher comes around the corner. Bypassing the two EMTs pushing the stretcher, my eyes look at the patient, whose face is Smurf purple, ringed with wet hair but I could still make out grey tints of color. Her eyes were closed and mouth slightly open with several blankets over her but her purple right foot pops out from under the blanket. Two nurses are in Bed 2 waiting as two more walk in following the stretcher, then another Doc and the pediatrician on call at the time, follow behind. And
with a push from Doc on my upper back, I trickle in last and stand near the back of the room.

The EMTs start giving their report as the blankets are pulled down from her as one nurse starts attaching one of those sticky monitors to her left breast, her right breast, and two on her abdomen. At this point, the woman is completely naked and purple. The nurses continue to move their hands on, in, and around her. The monitor lights up with a zero in the top right and the light that is usually going up and down, is simply moving horizontally across. A different nurse places the tube in the urethra, just above the vaginal opening. She continues to push the woman’s layers of skin away from the area so that she can clean and insert the tube. The woman is still completely exposed. Was she dead? What happened to her? A third nurse has connected oxygen with a mask over it so the woman now has a tube from her bladder, a tube in her nose, one in her mouth, and four monitors on her upper and lower chest within minutes. Lastly, warm blankets are layered over her body including a heating blanket that looks like a raft.

“What’s her temp?” one of the docs asks from behind.

“14,” a nurse replies. (This is Celsius, equivalent to about 55 degrees, Susan Ryan, 2010, personal communication.)

“Do we have another heating blanket we can put directly on her body and leave the one on top,” the doc asks again.

A nurse walks briskly out and comes back with another raft, or heating blanket. A tech standing next to me looks over and asks if I am doing alright.

“Yeah, thanks. Is she dead?”
“Well,” he said, “she is too cold for us to resuscitate or pronounce her dead.”

Completely confused, I stare at him.

He says, “they say you’re not dead till you’re warm and dead.”

“What!” I respond.

“Yeah, it’s complicated, but the body must be 32 degrees before we can do anything.”

Not dead till you’re warm and dead I kept saying to myself…Who are these people doing this work? What goes on in their minds, their hearts and their souls when they go home at night or early in the morning? How do they do this?

These stories – and my reflections and reactions – are filled with the tensions, the expectations, the devastations and the compassion of coordinating care. Even more, the stories represent the changing communicative contexts in which patients, families, and providers reweave the meaning of life and death and reorganize how decisions are made around end of life. These stories are invitations for you to enter the places to get a feeling for being there. It is impossible for you to feel exactly the things I felt, but the important thing is to hold on to what it’s like to work here, and to experience these places.

Attitudes Toward Death and Dying in Society

The factors that contribute to our culture’s handling of serious illness, suffering, and death can be overwhelming. Many believe that our society is “death denying.” This idea has become widespread being reflected and produced in mass media where death itself has become taboo, or the “elephant in the room” (Seale, 1998). It is also supported by the prominent story of *The Death of Ivan Illich* (Tolstoy, 1976) that underscored how the medicalisation of death that he felt, makes death an alien experience as no one –
neither his family members nor his physician – acknowledged he was dying. Instead, those around him continued to believe that he is only sick and not dying. Ivan’s daily activity becomes routine and discouraging and believes he is surrounded by artificiality. As a result, he dies alone in his agony but experiences extreme joy as he stretches out and dies. Additionally, Callahan (2000), a leading critic of the American way of death, describes the tension between fighting death and accepting death because the United States, more than many cultures, is a death-avoidant culture or a culture committed to survival and saving lives at all costs (Cassell, 2004). And at what cost? Most people know that most healthcare dollars are spent at the first and last 30 days of life, underscoring the real cost of our fears and the natural tendency of budget fixers to look at these cost (Susan Ryan, 2010, personal communication). Emotional tolls of these lengthy deaths do not go unnoticed.

Discourses of death as taboo and death as alien give rise to the construction of the reality of death. And these constructions give rise to meanings of death but also to the everyday practices through which death is handled. Charmaz (1980) argues that these perspectives are embedded with values that shape and are shaped by our own experience as well as others’ experience with death and dying. The values we hold about death and dying are changing the way many of us experience death. Even more, advances in medicine and medical technology have changed the way in which Americans are dying.

Quick and intense deaths caused by infectious disease, accident, or injury is no longer the way most of us die (Callahan, 2000) with sudden death being responsible for 10% of deaths and chronic illness being responsible for 90% of deaths (NPCRC, 2008). As Ragan, Wittenberg-Lyles, Goldsmith & Sanchez-Reilly (2008) state,
The preeminence of medical science and advanced technology, which have led to the eradication of many diseases once considered death sentences, permit us the belief that we have conquered death, that it is no longer the inevitable, natural conclusion to life. (p. 5)

Callahan (2000) summarizes that medical science and advanced technology has resulted in longer lives and worse health, longer illnesses and slower deaths, and longer aging and increased dementia. In essence, the medical process of dying has replaced the act of death.

As a result of the changing contexts in which we die, Americans are experiencing death differently today than in the previous century. Of the 2.3 million deaths that occurred in 1995, more than two-thirds were older than seventy. Additionally, as more causes of death result from chronic conditions, people are living in a dying role longer, thereby increasing the necessity for communicating more frequently with dying persons (Bern-Klug & Chapin, 1999). This necessity ultimately generates difficult problems in the way we live our lives and the way we make decisions around how we want – and can – live and die (Callahan, 2000).

How and when do you want to die? How much pain and suffering will you be willing to bear, and for what reason? What do you owe others when you die? These questions grow out of a larger fear of death and highlights how talking about death affects the way people communicate with and about a person who has a terminal illness. In fact, the presence of someone who is dying can be uncomfortable on both an individual and social level, creating great apprehension with the dying during a process that is undoubtedly intimate for families of a dying person and for providers caring for

Prominent illustrations of ways in which death is forbidden in much of modern society include language of ordinary discourse, professional speech and communication about dying. It is important to pay attention to these linguistic practices because naming helps to define and to determine reality. How we speak says a good deal about who we are and the attitudes we hold…(p. 36).

The phrases, for example, “not dead until your warm,” “not dead till they are warm and dead,” “next stop, heaven,” “letting go,” “she lost her battle with cancer,” “he fought until the end,” “she has passed away,” “he has gone to a better place,” “expired,” “coded” and “not till the doctor pronounces them dead” are examples of how our thoughts, reflections, and values about death and the dying process are created, maintained, and experienced.

The words, fears, struggles, and experiences shape our meanings and understandings about by death. Interestingly, the shaping of these meanings are taking on new forms, thereby forcing new questions about them. Recent awareness that death causes human dilemmas has been transformed into a vision of death as the new social problem of our time (Charmaz, 1980). But to define death as a problem suggests that there are solutions to it. For example, many Americans today see technology as an escape from the inevitability of death and believe that technological advances will be able to fix any bodily damage created throughout their lives (Ufema, 2004). Furthermore, in such times of uncertainty, previous recipes for handling the dilemmas that death poses are
called into question, thereby encouraging us all to re-think our understandings of nature and death and ultimately of what it means to live a human life (Babrow & Mattson, 2003; Charmaz, 1980). This matters because discourses around end of life care have enormous emotional, physical, social, material, spiritual, and financial costs for all involved.

In summary, this project examines how two different, yet overlapping clinical discourses in which death and dying play a role – emergency and hospice – are composed and organized. Further, the research questions guiding this project are as follows. First, what is the nature of talk in the ED and in the hospice? Second, how do providers' own work practices influence talk and how does talk influence these same practices? Third, how do these practices shape a particular orientation toward life and death? Finally, how does the talk in both environments enable and constrain providers' professional and personal ability to make choices around the end of life?

Understanding these discourses and relationships will enrich understanding about communicating around the end of life and provide several additions to the current literature. First, such a study adds to our scholarly understanding of end of life communication. While several theories exist as to why end of life can be painful, these theories are largely rooted in a biomedical perspective or have been rooted in an interpersonal context without conceptualizing the everyday ways in which space, place and language influence end of life care. Second, the study examines the role organizational realities of death and dying play in the construction and organization of medical care. Third, the study sheds light on the ways patients, families, and providers experience pain, hope, and suffering through distinct – yet overlapping – types of work. In so doing, it will help understand medicine as a form of work and the work medicine
demands of individuals. Lastly, the study provides a picture of what living and dying look like in clinical settings, a representation that has implications for education, policy, intervention and practice.

Dissertation Overview

Chapter two provides an outline to the relationship between talk and discourse as it is understood in this study. Specifically, I will describe how discourses often intersect and compete around care at the life. Even more, I describe specifically how I understand these concepts and what they mean for this study.

Chapter three reviews the literature on end of life talk and discourse. It describes the role of language in shaping understandings and describes the way the literature produced two distinct ways of talking and ways of knowing in clinical settings. First, the literature says much about the voices of medicine or what medical people actually do. I will review the literature on medical talk within a clinical, emergency setting where communication is curative. Second, I will review how the literature describes medical talk within a hospice setting where communication is often understood as comfort.

Chapter four provides the conceptual framework of this dissertation. First, I will underscore relevant and appropriate literatures rooted in dialogic thought as they relate to medicine as organized work. Then I turn to a review of end of life communication where I examine key concepts as they relate to health communication, such as an interpersonal approach, a social construction approach, and a critical cultural approach. Together, they emphasize the conceptual framework guiding this study.

Chapter five outlines my methodological assumptions and commitments that guide my research questions and describes the sites of this study as well as the empirical
methods of data collection and analysis. Furthermore, this chapter outlines my role and positioning as a researcher and its impact on what I saw and didn’t see and claimed and didn’t claim as I moved seamlessly and not so seamlessly between roles as a communication scholar, a sister, a daughter, and a granddaughter. This chapter describes the people, place, layout, smells, and sounds as well as a brief overview of their histories in order to begin illustrating how both of these sites organize care at the end of life.

Chapter six is a “crisis chapter” as a consequence of “leaving the field.” More specifically, it is a descriptive narrative that illustrates the tensions and contradictions between what I had learned about death and dying and what I experienced in both of these sites. Even more, it is designed retrospectively to gather a “feeling” for the plurality and competing voices at the end of life that often cannot fit dominant understandings of the meanings surrounding life and death. This chapter complements the way this project started, with the voices of others in an effort to get a glimpse of clinical life and what it means to live and die in the 21st century. Therefore, this chapter is about a voice that unwaveringly dedicated the past two years to living, talking, listening, reflecting, crying, and laughing with the individuals who have given birth and life to this project in the face of death. It is a personal narrative with a hope of also giving you, the reader, another understanding of my ethnographic journey.

Chapters seven and eight begin the data analysis. Specifically, chapter seven describes the nature of the hospice. That is, the discourses and structures of organizational realities that set the stage for coordinating care at the end of life. Even more, this chapter considers the way interactions between organizational norms and the complexities of individuals’ experience around death beget various strategies as well as
unintended practices. Chapter eight is similar insofar as it describes the nature of the emergency department through exposing the norms, rituals, and realities that help configure their environment. In doing so, both chapters underscore how their everyday activities and the environment in which they work produce and transform a particular orientation to understanding life and death. Furthermore, these chapters underscore the communication dilemmas confronted by doctors, patients, family members, and health care teams in the delivery and acceptance of emergency medicine and hospice medicine. In no way, however, are these chapters or this project written in favor of one kind of medicine as against another kind of medicine, or against medicine in favor of an elimination of medicine. Rather, it is written to provide a comparative discussion of multiple discourses in order to suggest new “scripts” for communication that may begin transforming health beliefs and communicative practices in the field of medicine.

Chapter nine juxtaposes the norms, experiences and nature of both sites. Further, this chapter returns to these same narratives in chapter one to not simply describe what is being said, but rather describe what this talk is doing to our understandings around death. Even more, this chapter describes how providers’ language use attempts to tame meanings surrounding death thereby concealing them from critical engagement.

Finally, chapter ten offers a conclusion including the implications of practice and theory, and lessons learned in conducting the study. In essence, it offers conclusions by reviewing the questions and problems that have shaped and given life to this study. Furthermore, it summarizes key findings and features three contributions to our discipline—theoretically, methodologically and pragmatically. Lastly, this chapter
discusses the implications of these contributions and directions for future work at the intersections of health and organizational communication, particularly around end of life
Chapter 2:

Talk as a Form of Discourse

This project focuses on how discourses influence the way we understand life and death. Specifically, I have used the phrase, “the competing discourses of care” several times and I want to clarify its meaning. For me, a particular discourse, like a particular model of care, orients us to the world a particular way. Even more, a discourse of care, like emergency or hospice for example, gives us a particular understanding and way of feeling about death. A particular language influences how we value things and what we take to be true, right, and worthy of pursuit. Therefore, to say that there are competing discourses of care is to say that there are competing ways of understanding life and death, arising with different vocabularies, different ways of interacting, and making decisions. My interest is not which ones are competing, but rather how each discourse and way of understanding life and death is produced, reproduced, and maintained.

By focusing on how discourses orient us to understand life and death a particular way, I have been most interested in language and the way we all use certain vocabularies to achieve certain ends and preference certain distinctions over others. Therefore, I take language seriously and have gained insight from Watson (2002) who underscores that language is not just a tool we use to describe actions; rather when we speak, we also act. Even more, we bring things into being in large part through the language that we use. And when we speak, we put boundaries around meanings. For example, think how many of us feel when we hear or see the word, cancer. The words used to describe the diagnosis, the treatment and remission have set distinctions around what it is, and not. People “battle” cancer. People “lose” their “fight” with cancer. People “win” their
“battle” with cancer and become “survivors.” People “kick cancer’s ass.” Some people “lose” their hair when they have cancer. People become “cancer patients” rather than people with cancer. These are some competing discourses that have gained considerable momentum through the words and language the medical community, lay people, and media use over and over. In order to understand the dynamics of language and talk around medical care, I am borrowing insight from a set of literatures whose careful analysis of thinking about discourse and language informs my study. The literatures emanate from organizational communication, a field that had much to offer health communication research.

Like many scholars in organizational communication, I believe that language is constitutive. Therefore, organizations like the ED and hospice are discursive constructions because discourse is the very foundation upon which organizational life is built (Fairhurst & Putnam, 2004). The term discourse, however, has a variety of meanings, so to distinguish them in this study, I turned to Fairhurst and Putnam (2004). Discourses for them are broad and general systems of thought. And discourses (with a small “d”) are where relationships and interactions are accomplished through language in use. A critical note, then, is that discourses are local accomplishments.

For example, silences, whispers, and screams move people to act and interact in some ways and not others based on certain Discourses or systems of thought. Likewise, Discourses carry values, beliefs and ideas that encourage us to think in some ways and not others. They even encourage us to hear in certain ways too, and actively not hear in other ways. What is more, Discourses organize and naturalize the world in particular ways. How they order and naturalize meaning is better understood by borrowing insight
from the three orientations to organizations as discursive constructions as described by Fairhurst and Putnam (2004). I will discuss them here because they are must useful for understanding the relationship between discourse and reality and how certain Discourses within an ED and hospice become organized, naturalized, and coded around end of life.

The first orientation, “object” understands organizations as detached from members’ action and therefore, an already identifiable formed entity. As a result, organizations exits independent of participants’’ activities and discourse is seen as reflective of participants talk (Hosking, 1988). This orientation, however, has introduced variety in the way theorists understand and define discourse, specifically moving more towards Discourses (Fairhurst & Putnam, 2004; Fairclough & Wodak, 1997). Even more, “these scholars trace linguistic patterns across broad contextual arenas as opposed to doing detailed microanalyses of discourse. This inability to describe and detail language patterns has led some analysts to claim that critical discourse studies are ‘discourse-lite’” (Fairhurst & Putnam, 2004, p. 12-13). Although this move to Discourses has shed important light on the powerful cultural and institutional forces that permeate beyond language, this orientation downplays the role discourse places in constituting organizations. The downplaying of the dynamic processes by which discourses operate, however, is attended to in the next orientation.

The second orientation, the “becoming,” seeks to uncover how organizations organize in the first place, continue to stay organized, and sometimes become “unorganized” (Hawes, 1974). Organizational discourse is dynamic. This orientation privileges the processes of organizing and the way that discourse produces, reproduces, and maintains these processes. It examines both discourse as language in use and
Discourses that reside in power/knowledge formations. The aim of this orientation focuses on the question, “What is organizing about discourse?” (Fairhurst & Putnam, 2004, p. 13). This orientation, however, has a difficult time conceiving of organizing and organization particularly over time, space, and shape.

The third orientation, grounded in action, focuses on the actual process of organizing rather than organization. Understanding the process of organizing over time and place is guided by the question, “How is the ‘organization’ anchored in what Giddens (1979, 1984) refers to as the ‘duree’ or the continuous flow of discursive conduct?” (Fairhurst & Putnam, 2004, p. 16). This orientation is less an extension of the becoming orientation and more a separate perspective that treats actions and structure as mutually constitutive whereby structure is both the medium and the outcome of social action (Giddens, 1979). For example, the environment or structure of the ED can be described as complex, urgent, fast, and chaotic. This type of structure then calls for certain behaviors or responses and especially allows certain behaviors and responses to be acceptable. For example, sarcasm is used often in the ED as a way of “coping” or “diffusing a patient or colleague’s energy off.” Additionally, “not having enough time” becomes an acceptable response to doing things particular ways given the structure in which it is happening. Therefore, the chaotic structure of the ED is endlessly constructing – and calling for – certain behaviors and responses to situations. And at the same time, these responses always naturalize a structure of urgency and quickness that again becomes the means for organizing certain forms of action.

I have chosen to introduce these three orientations as a way of understanding the ED and hospice as discursive constructions. Specifically, focusing on the “becoming”
and “grounded in action” orientations are most useful to push the boundaries of our own understandings of language, discourse, and organizing. More importantly, these two orientations open the possibility for everyone to consider alternative views of organization, discourse, and language without abandoning our own beliefs and value systems (Fairhurst & Putnam, 2004). These orientations will serve as maps throughout this project in order to think about unique ways of talking about the way Discourses are organizing meaning around the end of life in interesting ways.

Because language is vital to understanding the relationships between discourse, organizing, and care, it is important to understand how dominant cultural discourses like those about death encourage and constrain the language available to us. For example, a cultural discourse in hospice orients many of us into believing that their care is endlessly different from what we would experience in another setting. This orientation is encouraged and organized as a discursive formation – a particular way the world is articulated or the way distinctions are made and joined together (Broadfoot, 2003; Deetz & Radford, 2008). In general talk, literatures, and as we will see in the hospice site is presented as being different from any other place. This presentation is spoken, written, mediated, and unmediated (Foucault, 1970). They are internally consistent among providers, identifiable groups of hospice, or even particular movements around living wills or quality of life. Further yet, their discourse communicates values and beliefs that are held to be normative and persuasive, thereby organizing the way we talk, think, and write about death (Foster, 2007).

In essence, a discourse is a set of interconnected concepts, expressions, and statements that constitute a way of talking and writing about end of life framing and
influencing how people understand and act with regard to care giving. Discourses distribute meanings around life and death. They also confirm what can be said about death and what should be concealed about death (Broadfoot, 2003). Understanding a discourse includes identifying how language is used in making distinctions between what is a good death, what is a right way to die, and what is worthy in the pursuit of living and dying. It also includes identifying what and whose values and interests are carried with those distinctions in coordinating decisions around end of life (Deetz, 1992).

In order to understand how discourse refers to a system of language that coordinates decisions within clinical settings, I borrow heavily from Broadfoot’s (2003) exemplary study of a genetic clinic. In her study, she describes the meeting that took place when parents sat down with doctors and clinical providers to discuss treatment options for their child with a genetically-based disorder. Three different discursive formations surfaced in their talk organizing knowledge, concepts of a person and notions of how life and death work. In her observations, each used the discursive formation they drew from as the way the world was when they were receiving care. Therefore, the focus is on the micro-practices by which persons, knowledge, and collective decisions are produced in particular moments and how discursive formations organize meanings, create distinctions, and provide scripts for behavior, thereby excluding, denying, or marginalizing others (Broadfoot, 2003; Deetz & Radford, 2008).

How we live, breathe, act, and talk depends on existing discourses, our access to them, and the interests they represent (Broadfoot, 2003; Weedon, 1997). To understand, imagine a meditation room full of mediators and meditating bodies. For the most part, the image is quiet and free from any movement or gestures. Occasionally, however, someone
will clear their throat, cough or adjust their pillow or mat. Often, one movement will trigger another movement. According to Pagis (2010), “this orchestra of sound and movement merely reflects human nature and human sociality – we tend to react to others, even when surrounded by silence” (p. 17). This same orchestra of sound and movement can be seen in other public places: the classroom, the church, the hospital, and so on.

For example, how do you feel when you walk into a hospital or hospice? What do you do when you walk into those places? How do you walk? Do you talk? What does it sound like? How do you act? What kind of shoes do you wear? What do you smell? What do you hear? Do you follow a set of built-in rules and norms when you enter a hospital or hospice? Without a doubt, these places influence how we live, move, breathe, and talk. Likewise, our actions influences how others live, move, breathe and talk. In doing so, we actively read silence, gestures and breath as we would read speech, turning silence into a form of communication (Pagis, 2010).

As silence becomes something to be read, we simultaneously sort through multiple discourses as they enter our thoughts. During this sorting, our thoughts must connect and coordinate with others in order to make sense. According to Broadfoot (2003),

A discursive formation or form of rationality or consciousness is a coordinated ensemble of diverse and often oppositional entities, that once disarticulated, loses their synchronicity. When discourses are articulated as a group, they form statements and conceptual figurations (discursive formations), set of anonymous rules and structural principles (discursive practices), complex interrelations across sites (discursive fields) and when joined by the non discursive (discursive
apparatus), discourses produce objects, subjects and relationships, deploying power and shaping historically specific meanings…and coherence that appears in such a discursive formation is then dependent on the regular dispersion of these individual discourses in multiple institutions, material practices and subjects (p. 42).

Therefore, discourses that we adopt can affect what we believe and how we feel about life and death.

Discourses around end of life take many formations. Settings like a ED and hospice are comprised of deeper meanings of speech that determine what can be said and what can not be said. Discourse, like disease, binds and orders truth and time. As Foucault (1973) argues,

The order of disease is simply a ‘carbon copy’ of the world of life; the same structures govern each, the same forms of division, the same ordering. The rationality of life is identical with the rationality of that which threatens it. (p. 7)

Even more, Foucault (1973) explains that we are dealing with systems that are both natural and ideal: “Natural, because it is in them that diseases state their essential truths; ideal insofar as they are never experienced unchanged and undisturbed” (p. 8). Therefore, in the rational space of disease, discourses occupy a unique role that is hardly avoidable and endlessly neutralizing and ordering the essences of the disease process (Foucault, 1973).

Discourses are pervasive, ubiquitous, and are exercised through multiple, strategic and relations that are filled with tension (Foucault, 1977). For Foucault, “discourse is a way of constituting knowledge, it constitutes the nature of the body, conscious and
unconscious mind and the emotional life of the subjects it seeks to govern” (Weedon, 1997, p.104). This governing is exercised rather than possessed, producing relations based on knowledge, relations about how the world works, and relations about the meaning of life and death (Broadfoot, 2003). These relations, however, unfold through our specific ways of knowing about death and dying and our access to them.

Summary

Studies and descriptions of talk in emergency medicine and hospice settings are similar. Talk and language at the ED and hospice frame and influence how we understand life and death and how we hear and act with regard to living and dying.

The next chapter will focus on the intersection of the voices and discourses of care that are organizing thoughts, beliefs, feelings, and decisions about life and death. Attending to what occurs at the intersection will begin to expose the nature of experience, the role of language, and the recognition of voice and subjectivity. Doing so reveals how we can begin to understand how moments, gestures, words, and silences within an emergency and hospice setting actualize meanings, vocabularies, feelings, and decisions about how we want to die and live.
Chapter 3:
Discourses and Languages in Medicine

Analyzing what is possible to know, do, and be in particular contexts is the focus of many communication studies about cultural talk (Lupton, 2004). Spoken communication produces meaning in practice. That is, our actions, words, and silence help us make sense of an experience (Hirschmann, 2000). Further, our talk organizes our thoughts and decisions. My study of talk helped me understand what people believe about death and dying based on the language that is available to express their meanings and interpret those of others.

Specifically, the talk I heard in an emergency department and hospice helped me understand how language organizes knowledge, feelings, relationships, and notions of how life and death work. I heard firsthand how language makes certain decisions about end of life care possible at the expense of others. The hospice and the emergency department are unique settings insofar as their histories and meanings shape a particular way of talking about medicine and care. Therefore, I will first describe each site to illustrate the dynamic relationship between the environment and the language usually described as embedded in them.

The Language of Emergency Medicine

The demand for emergency services has been an integral feature of modern health care in the United States and other nations. Despite all the attention on providing health care to Americans, emergency departments (EDs) continue to serve as the health care safety net for up to 15 percent of the population (Zink, 2006). It is important to note that I have chosen to term “ED” rather than the routine “ER” for a few reasons. First, many
emergency physicians feel that the term emergency room is outdated and prefer the term emergency department or ED, especially after 1961 when full-time emergency physicians began practice (Zink, 2006). Second, one of the ED physicians I observed told me the distinction is that the ER has evolved from a single room to a large multilayered department, thereby making ED more accurate unless in a small rural environment (Susan Ryan, 2010, personal communication).

Emergency medicine has always been about the patients. While all specialties in medicine can claim to have patients as their focus, only one specifically has emerged to take care of anyone, with anything, at anytime. Emergency medicine came about differently from traditional medical specialties (Zink, 2006). It was fueled by new social and political conditions and responded to specific needs between the well and the poor, regardless of race.

One particular way health care changed post World War II was an infusion of public reliance on hospital emergency rooms (Zink, 2006). As patients began to seek out care in ERs in the 1950s, the medical expertise for providing quality emergency care was lacking. Specifically, medicine was put into a position of having to catch up to the public demand, but the professional solution to the ER problem did not arise until the 1960s. Some of the physicians who would provide the solution and would later have significant roles in the founding of emergency medicine were in their formative years or were starting their careers in the 1950s. (Zink, 2006, p. 2)

General practitioners and house calls also gave way to emergency care, which slowly subverted the ER into an alternative, costly, primary care setting. Many younger
physicians at this time were making less calls and sending more patients to their offices or the hospital, places that had better equipment for a proper exam, and better resources for treatment and diagnosis (Zink, 2006).

The post-World War II era brought increased business and increased incomes to physicians (Zink, 2006). In so doing, it also created a community that was fascinated with the physician as a professional, scientist, god-like healer. But as patient admissions increased, the ER was generally viewed as an annoyance rather than an opportunity for medical care.

From 1965 to 1970, ED visits in the U.S. rose from 29 million to 42 million per year, in part because of the increase in Medicare and Medicaid (Zink, 2006). In the mid 60s, the poor and elderly viewed the hospital as a place where medical care was based, especially in the US. Specifically, hospitals had become little fiefdoms of health care in most communities, with outpatient clinics and private physician office buildings adjacent or annexed to the hospital building. For patients who were now entitled to care by way of having Medicare or Medicaid insurance, presenting to the ED at a hospital complex was the simplest and most convenient way to gain entry in to a system that could seem imposing and confusing from the outside. Patients understood that even if their problems were not very acute or severe, they would be seen and treated in the ED and referred to outpatient care in the same system. Even patients with a regular doctor used the ED in the evening and night hours when accessing their physician was becoming increasingly difficult. (Zink, 2006, p. 56)
Emergency medicine grew up at a time when American medicine was becoming more “corporate.” The increase in hospitals, insurance companies, and medical specialists in line with the vast amount of money that was changing meant that health care would become a major industry (Zink, 2006).

With the continuous changes in medical health care, increases in Medicare, health maintenance organizations (HMOs), and primary care physicians should have decreased ED visits. However, this has not been the case. Arguably, the most consistent aspect of health care in the past 30 years are ED patient visits (Zink, 2006). Specifically, U.S. ED patient visits were 81 million in 1980, 96 million in 1992, and 114 million in 2002 (American Hospital Association, 1974-2004).

Many believe one factor that has contributed to the increasingly high admission rates to the ED is the passage of the federal Emergency Treatment and Labor Act (EMTALA) in 1986. This piece is legislation was,

Intended to outlaw the practice of patient dumping from one hospital to another. As the healthcare marketplace struggled in the 1980s, some hospitals refused to accept, or inappropriately transferred indigent or uninsured patients to other hospitals – usually to municipal or charity hospitals. A few highly publicized bad outcomes from this practice prompted Congress to act. EMTALA mandated that all hospitals participating in the Medicare program must provide an ED screening evaluation and stabilization or arrange an appropriate transfer without consideration for the patient’s ability to pay. (Zink, 2006, p. 274)

Interestingly, after EMTAL, visits to the ED experienced an acceleration. Additionally, the overcrowding of waiting rooms also increased by the closure of hundreds of mostly
smaller U.S. hospitals and emergency departments in the 1990s (Zink, 2006). Further, the increase in ED admissions as well as the overcrowding of waiting rooms unfolded in line with an increase in the estimated 45 million people who had no insurance.

ED visits for critically ill patients have increased as the population ages and sicker people are treated outside of the hospital, despite many assumptions that the increase in admission is a result of “nonacute” or minor illnesses (Zink, 2006). But since the 1950s, “patients have figured out where they can and in some cases, must go when the health care system cannot provide timely care. People vote with their feet, and the steady march of patients to EDs in the United States and worldwide over recent decades suggests that emergency physicians are providing something that is lacking elsewhere in medicine” (Zink, p. 275).

EDs are viewed by many as a significant problem to outrageous health care costs because so many people over rely on them (Zink, 2006). Others believe if only we could get the people out of the ED who don’t belong there, we could bring costs under control. Arguments abound. But despite which argument you choose, the demand for emergency services is remarkable and has been a dominant trend of modern health care, thereby changing the way emergency medicine is practiced and the way it manages its care environment. Zink argues that the expertise of emergency physicians has increased more than in any field of medicine. Because this is a field and a place so many of us turn to in a moment of crisis of life, death, or disability, it is a place whose history reveals much about the role language plays in order to respond to such demands while remaining the only specialty to take care of anyone, with anything, at anytime.
Emergency physicians have standard protocols and conversations when patients arrive. One example of clinical interaction in the ED I witnessed was when I was shadowing Dr. Mead. I recorded this interaction on a scratch piece of paper when I was observing. Therefore, all words were spoken as is and I have not cleaned them up for the purposes of this study.

Doc: I’m Dr. Mead and this is Carey, one of our students. What’s going on that brought you into the hospital?

Patient: I fell down some stairs and my neck hurts, and I have a bad headache.

Doc: How did you fall?

Patient: I was wearing flip flops.

Doc: Where does it hurt?

Patient: Right here [touches the back of her neck and head].

Doc: When’d you fall?

Patient: A few hours ago.

Doc: Any previous medical history?

Patient: Depression [keeps touching her neck].

*Doc walks closer and looks in her ears and then puts pressure on her neck asking where it hurts. He touches her actual body for about a minute.*

Doc: I’d like to get a Catscan and Xray of your neck and head to make sure there is nothing else there.

Patient: Do I have to go in a tube because I am Closter phobic? [actual patient’s words]

Doc: You’ll be alright. Do you need anything for pain – Ibupofen, something stronger?

Patient: Something stronger.
Doc: Vicodin? Percocet?

Patient: Vicodin hurts my stomach.

Doc: Well let’s try Percocet. Ok, I will be back in to tell you the results when we have them.

This standard form of interaction – albeit with different information – is known as a clinical algorithm (Groopman, 2007). The patient presented her story and the physician translated her story into an actionable list to reach a therapy or diagnosis. In this case, the patient’s story describing pain in the back of her neck from falling is interpreted into action. Following a series of standard questioning and answering, this action translates to ordering a Catscan and Xray of her head and neck.

According to Groopman’s (2007) book, *How Doctor’s Think*, the trunk of the clinical decision tree consists of a patient’s major symptoms or laboratory results, contained within a box. Arrows branch from the first box to other boxes. For example, a common symptom like “sore throat” would begin the algorithm, followed by a series of branches with “yes” or “no” questions about associated symptoms. Is there a fever or not? Are swollen lymph nodes associated with the sore throat? Have family members suffered from this symptom? Similarly, a laboratory test like a throat culture for bacteria would appear farther down the trunk of the tree, with branches based on “yes” or “no” answers to the results of the culture. Ultimately, following the branches to the end should lead to the correct diagnosis and therapy (Groopman, 2007).

Clinical algorithms may be useful for run-of-the-mill diagnoses and treatments, but they quickly fall apart when a doctor needs to think outside their algorithmic boxes, when symptoms are vague, or multiple and confusing, or when test results are inexact.
(Groopman, 2007). In such cases – the kinds of cases where we most need a discerning doctor – algorithms discourage physicians from thinking independently and creatively (Groopman, 2007). Instead of expanding a doctor’s thinking, they constrain it. But how do doctors think? And how should doctor’s think in clinical settings, like an emergency department?

Medical interactions in a setting like an emergency department constitute a significant part of the day-to-day practice of clinical medicine (Mishler, 1984). Therefore, talk in this setting has been understood in the literature as a primary source of understanding clinical work. Whose interests does their talk serve? How does it shape and organize the medical encounter as a particular type of language? What type of relationship between patient and physician does it affirm? These questions grow out of a concern wondering whether current forms of clinical practice respect the dignity of patients as persons and recognition of their problems within the context of their lifeworlds or meaning (Mishler, 1984). Drawing from this literature, the grounds for interpretation shift from assumptions based on a biomedical model of physicians to the perspective of patients and the lifeworld contexts of their problems. Therefore, this approach views language seriously – it is not “mere” talk, but the work that doctor, nurse and patient do together as an essential and critical component of clinical practice (Mishler, 1984).

This particular understanding of what the patient means in medical interactions tend to be defined as technical, regardless of whether evidence based medicine or clinical algorithms are in play (Mishler, 1984). From these perspectives, laboratory tests and the results of physical examinations take priority over what can be learned from talking with
patients. The impact of a biomedical model on clinical training, however, is profound. Arguably, hospitals in general, and emergency departments in particular, are the primary settings within which medical students, interns, and residents see patients, yet they have little opportunity to work with patients in the context of general medical practice, as in a primary care setting (Groopman, 2007). Diagnosis, care, and treatment in these settings are short-term, albeit they can be the most important hours for the patients. Even more, they often focus on single episodes of illness in patients who students are unlikely to see again. Thus, talk and training here differs in significant ways from talk and training in other settings such as primary care or a hospice setting (although this is changing), where physicians and nurses are believed to enter into long term relationships with patients whose life circumstances they become familiar with as they attend to a variety of episodes and illnesses over an extended period of time (Mishler, 1984).

A diagnosis, as described in the literature, is a way of interpreting and organizing observations. According to Mishler (1984), a diagnosis is no less real because it is dependent on what physicians ask and what they hear, and on what patients report and do not report than it would be if it were based on the results of physical examinations and laboratory tests. Since the discovered illness is constructed and not found, it is, in this sense, partly a function of the talk between a patient and a physician. Thus, the study of talk is central to an understanding of both illness and the meanings of life and death. How end of life communication produces and reproduces knowledge about particular medical conditions; how patients see and describe their illness; how providers describe and narrate their cases to their medical colleagues; how providers seek to persuade one
another about diagnoses and clinical management and how they justify and legitimate their knowledge and opinions is central to this project (Mishler, 1984; Foster, 2007).

Emergency medicine, therefore, is a communicative activity (Eisenberg et al, 2005). Unlike other areas of the hospital, the ED is unbounded, meaning that their workloads, patient admissions, flow of work pace, and work environment is essentially uncontrollable. Moreover, the demands on emergency services are increasing during an exceptional time with nursing shortage, rising insurance rates and rising uninsured individuals thereby implying a new environment for providers, patients and families (Eisenberg et al, 2005). For that reason, emergency work involves multiplicity, caring for numerous patients with highly variable complaints simultaneously.

The high level of uncertainty that characterizes ED work in the amount of background information about patients and the need to make difficult decisions before critical data, demands a continuous shifting of framing and communicating. Furthermore, ED work is provided under significant time constraints with stringent charting practices, which can cause a narrowing of focus and a rush to judgment (Eisenberg et al, 2005). Additionally, the lack of long-term relationships with patients leads ED staff to receive little or no feedback about the results of their care, making it difficult to learn from experience. In other words, there is little opportunity for reflective practice (Schön, 1983). Much of ED work is routine, and the riskiest procedures are done only sporadically, in contrast to other professions, such as surgeons or cardiologists, where the riskiest maneuvers are performed up to several times a day (Eisenberg et al, 2005). Together, these norms reveal emergency work to be an important environment in which to study communication and its impact on important health outcomes like end of life care.
Unlike most other industries today, health care remains highly fragmented by discipline and function (Schön, 1983). This fragmentation penetrates deeply into healthcare organizations and presents challenges for effective cross-functional communication. For example, EDs are separated by discipline and function thereby organizing significant obstacles to effective communication. Consequently, talk in EDs is internally fragmented by professional barriers separating physicians from nurses and nurses from interns, residents, techs, aides, EMTS and externally fragmented by the frequent presence and influence of other specialties such as consultants, pre-hospital service providers, laboratory, radiology, and others. Despite years of effort to create effective cross-functional healthcare teams with some success, they still remain mediocre since most healthcare providers identify more strongly with their particular function or profession (nursing, radiology, cardiology or pediatrics) than with their home institution or healthcare system (Eisenberg et al, 2005).

Understanding EDs as communication environments directs attention to how interaction processes construct and maintain ED culture, as well as to which patterns of interaction are likely to lead to less effective decisions and medical errors (Eisenberg et al, 2005). A significant element of such an analysis focuses on politics of participation in decision making, that is, how certain interests and values come to take precedence over others. Said differently, when EDs are viewed as communication environments, the rhetorical, performative, material, physical, political and narrative quality of interaction in these settings is underscored as an attempt to understand the basic forms of knowing (Eisenberg et al, 2005; Foster, 2007).
A useful conceptualization for understanding the basic forms of rationality within emergency medicine is Browning’s (1992) discussion of lists and stories as forms of organizational talk. According to Browning, two forms of rationality operate in every institution. The first, technical rationality, involves classification and making lists. Scripts, lists, algorithms, checklists, and formal processes are all ways of encoding the technical knowledge used by individuals in their work. And in any organization, much of the work consists of the enactment and execution of agreed upon lists or routines – ways of planning, organizing, designing, or producing a particular product or service, like delivering care.

A second kind of rationality is narrative, expressed in the stories people tell. Many organizational activities rely on story telling, from new employee socialization, to medical training and education, to organizational planning. In healthcare settings like an emergency department, patients arrive with a story and a significant component of medical training focuses on how to create a supportive environment wherein patients will feel comfortable to tell their story (Charon, 2006). Creating this type of environment, however, is more complex than a simple shifting from list to story. In fact, much of the literature describes talk and language as too “easy” or straightforward in an environment that is inherently complex, dynamic, and fluid. The complexity of talk beyond technical or narrative rationality is visible even in triage encounters, like the one I observed below between a nurse, a patient, and the patient’s father. Again, I recorded this interaction on a scratch piece of paper and therefore have not cleaned up –or changed–and words or phrases.

Nurse: Hi, what’s going on?
Dad: Well we are getting frequent fliers to the ER!

[Laughter]

Patient: I’ve had a terrible pain in my stomach and the past five times I’ve been here they have told me it is appendicitis.

Nurse: Do you have your appendix?

Patient: Yes.

Nurse: Does anything you do make it worse or better?

Patient: No.

Nurse: How long has the pain been going on?

Patient: A few weeks.

Nurse: Okay dad, I need you to step out while I ask her a couple questions.

Dad: OK.

Nurse: Alright sister, anything I need to know?

Patient: No.

Nurse: Any chance you are pregnant?

Patient: No!

Nurse: Are you sexually active?

Patient: No.

Nurse: Do you do drugs?

Patient: Well, yeah.

Nurse: Which ones?

Patient: Well, I do, I have done ahh weed.

Nurse: Okay, how often?
Patient: Like two months and again like two weeks ago.

Nurse: Okay, that’s not good for you, you know? Anything else?

Patient: No.

Nurse: Okay, I’ll get your dad and we’ll go back.

Dad: Now do you need me again to talk about insurance?

[Laughter and they walk back]

Talk in the ED, as this example illustrates, is not easily classified into stories and lists. Talk in this setting is candid, emotional, performative, and unpredictable. Even more, talk must endlessly be understand in a way that reflects a person’s lived experience, not just their medical experience (Charon, 2006; Schön, 1983). Recent work in medical education, however, focuses specifically on the critical role of narrative rationality in effective patient care (Charon, 2006; Eisenberg et al, 2005). Therefore, the relevance of Browning’s (1992) conception to the study of emergency medicine has to do with the continual interplay between these two competing forms of rationality. Patients and families come to the ED with stories and the institutional response is to seek to translate their stories into actionable lists. Browning (1994) elaborates:

The list is rooted in science and presented in a formula for action leading to controllable outcomes. The list represents standards, accountability, certainty, and reportability. Conversely, the story is romantic, humorous, conflicted, tragic and most of all, dramatic…stories fill the breaks in technical rationality. Narrative rationality fills the loose coupling between intentions and outcomes. (pp. 281-282)
The movement from story to list can be smooth, particularly when the patient reports routine or standard symptoms on what appears to be a direct disease process.

Doctors learn about diagnosis early on in medical school, which employs technical rationality to match patients’ complaints to specific diagnostic categories (Charon, 2006). Patients whose symptoms are vague, ambiguous, and suggest multiple conflicting diagnoses do not have a “good” story. And extreme pressures on time and space do not provide a supportive environment for the deliberate interpretation of patient narratives (Eisenberg, et al., 2004). Instead, the care team makes the best decision possible whether it is ordering more tests, collecting more data, or discharging the patient. These, in turn, transition into action, following the list that seems most useful (i.e., lab tests, diagnosis, treatments).

ED physicians routinely characterize patients who report clear, recognizable symptoms as having a “good story,” meaning that there is a simple and specific translation to an actionable list that at the same time rules out alternative diagnoses. Stories are used throughout a patient’s stay. For example, at the end of a patient’s stay, some degree of translation from list to story is always necessary. Essentially, there are three ways to leave the ED: discharge, hospital admission or death – each type of exit requiring a story. Discharge requires some form of treatment plan while hospital admission requires the team to persuade the patient that their condition is severe enough to be admitted to the hospital. And a patient’s death requires the care team to develop a convincing story to assure family and friends that they did all they could for their loved one. Thus, communication side-steps a thin line stretching from the meaning of technical
results and procedures on the one hand to the patient’s condition on the other (Eisenberg et al, 2004).

Emergency providers are the ones we go to when we can’t see our regular doctor, don’t have insurance, get sick in the middle of the night, are in an accident, stub our toe, can’t breathe well, don’t know how to care for someone, or don’t have someone to care for us. In essence, we ask much of this profession and this form of care whose history is as rich and complex as the language used for providing the care. It is a specialty whose meaning is as unique and diverse as the services they offer to anyone, about anything at any time. Dr. Brian Keaton, a past president from the American College of Emergency Physicians (ACEP) specifically articulates the profession and meaning of emergency medicine as the following:

Patients have spoken with their feet, seeking emergency department care in unprecedented numbers. We are the ones you come to when you’re really sick, possibly sick, or kind of sick and in need of rapid evaluation, diagnosis, and treatment. We are the place you come to when you cannot or will not wait for others to find a place in their schedules for you, and the site of medical refuge when you don’t know where else to turn. Despite limited resources, unrealistic expectations, and impossible demand, emergency medicine delivers on our promise to provide the best possible care to every patient regardless of their ability to pay or what time of day they choose to seek care. Alan Kay once said, ‘the best way to predict the future is to invent it.’ We’re in an inventing mode and are being presented with a historic opportunity to define the future of our specialty and of American medicine. The opportunities in emergency medicine
are endless and by choosing this career you will become a leader and a champion for the health care needs of your patients. The challenges before our health care system and emergency medicine are significant, but the rewards and honor of providing care to our communities are limitless.

Thus, the meaning of emergency medicine expands beyond the studies or ideas about medical talk described earlier. Furthermore, as far as claiming that talk is curative and translating things into clinical representation may be accurate, it is grossly over simplified. Understanding the competing discourses of care around end of life is much different in the ED from translating between list and stories. Relieving patients’ suffering is a goal of emergency medicine, and hospice medicine, although through different means. Their concerns may be the same, but their language, context, and quest in relieving a patient’s suffering are different.

The Language of Hospice Care

The meaning of hospice care is as complex and critical as emergency care. Hospice care dates back to the sixth and seventh centuries with the spread of Christianity in Europe. Though end-of-life care was provided at home, many monasteries accepted sick and dying people who did not have family to care for them (Ragan, Wittenberg-Lyles, Goldsmith & Sanchez-Reilly, 2008). This type of care for the dying provided at the monasteries continued throughout the Middle Ages and the Crusades and well into the seventeenth century, as people who were ill and dying often spent their last days being cared for by monks, nurses, and lay women (Ragan, et al., 2008). As the field of medicine began to evolve and formal hospitals were established, people who were ill and dying were treated and cared for in hospitals.
Care for people who were dying, provided through services of the church, shifted to institutionalized care in hospitals. Unfortunately, early hospital environments did not know enough to guard against germs and disease, which often meant that hospitalized individuals contracted and died from diseases other than those for which they were admitted (Ragan, et al., 2008). As a result, early hospitals adopted a poor reputation and were viewed as death houses. That said, early end-of-life care shifted again to home care provided by family members and neighbors.

Care continued at home despite advances in medicine and the established effectiveness of hospitals after World War II. As the knowledge of germ theory and the origins of disease were explained, medical treatments expanded, and the focal point of health care turned exclusively to saving lives and curing diseases. Individuals who were dying were seen as medical failures because they had no hope of advancing medical knowledge (Ragan, et al., 2008). In short, their care for “dying” was not considered within the scope of medicine.

The term hospice is of Latin origin, “hospes” meaning to be a guest or stranger. The term was first used by Madame Jeanne Gernier who founded the Dames de Calaire in Lyon, France in 1842. In 1879, the Irish Sisters of Charity opened their hospice, Our Lady’s Hospice in Dublin, Ireland. Mother Teresa, known as one of the founders of hospice care, opened the Kalighat Home for the Dying in 1952. From there, Dame Cicely Saunders started the first hospice program at St. Christopher’s in London in 1967. The religious roots of hospice care facilitated the growth of the movement and formalized care of the dying as hospice care. The movement spread, and the first hospice program in North America was established in 1974 in New Haven, Connecticut (Ragan, et al., 2008).
Patients’ experiences led to the opening of the first modern research and teaching hospice, St. Christopher’s in London in 1967. Saunders (2003), the founder of the hospice movement writes,

While working at St. Joseph’s Hospice in East London with the Irish Sisters of Charity, where I spent seven years on an extensive study on The Nature and Management of Terminal Pain (Saunders, 1967), I began making tape recordings of many of my patients…As I wrote then and many times since, what was being talked about was ‘total pain’ – ‘all of me is wrong.’ Without any further questioning [other than ‘tell me about your pain’] she had talked of her mental as well as her physical distress, of her social problems and of her spiritual need for security. Then, as now, I know that listening to a patient’s own tale of their troubles can be therapeutic in itself. As another patient said, ‘it seemed the pain went with me talking.’ (pp. 4-6)

Therefore, it was the intentional listening to suffering patients’ voices that inspired the opening of the first real hospice, St. Christopher’s in 1967. Similarly, this intentional listening to suffering patients’ has served as endless inspiration for this study.

The medicalization of grief and bereavement that occurred during the 1950s gained momentum as death began to occur less at the home and more at the hospital. According to Littlewood (1993), the medical community believed it was its responsibility to keep death away from the community. Yet little attention was paid to the dying process, and little care was given to those who were terminally ill (Ragan, et al., 2008).

Hospice is a care service that excludes curative treatment of illness, opting for holistic care of terminally ill patients. The primary goal in hospice care is pain and
symptom management at the end of the disease progression. And the paramount goal of hospice care, particularly out-patient, is to provide patients with the opportunity to die at home, surrounded by loved ones, with as little pain as possible (Ragan, et al., 2008).

Hospice provides a team approach to medical care, pain management, and emotional and spiritual support in order to individualize care for the person and their family’s needs and wishes. In order to be eligible for hospice care, the patient’s doctor and the hospice medical director use their best clinical judgment to certify that the patient is terminally ill with life expectancy of six months or less, if the disease runs its standard course. The patient then chooses to receive hospice care rather than curative treatments for the illness (National Hospice Palliative Care Organization, 2008). Hospice care focuses on the belief that every individual has the right to die pain free and with dignity, and that loved ones will receive the support to allow this to happen. For that reason, hospice is an inherently communicative environment that creates and maintains relationships through communication about the meanings surrounding life and death.

Making communication profound in hospice care is how people are together near the end of someone’s life; they create a new relationship at a time when life consists mostly of loss. And these relationships are often filled with intimacy and immediacy. Foster (2007), who worked ethnographically as a volunteer at hospice, discusses how patients did not care about her level of education, what she did for a living or where she was from. What ultimately mattered in her relationship with patients was the kind of person she was, the interests she showed in patients, and her commitment to being there to share their life. It is about allowing the relationship and communication to reveal itself,
learning to improvise and respond spontaneously to each other in the moment (Foster, 2007).

Improvising communication and care during a time when life is ending, building relationships is unique, as Western thinking about death centers around individuals understanding of self (Walters, 1994). When I started noticing the extraordinary forms of loss that occur at the end of life, I remember having coffee with a friend and colleague of mine asking her what happens when everything you’ve known, said, read, taught, touched, felt, loved, and feared, goes away and means nothing to anyone else? What is left of us? She smiled and touched her heart and soul and said, “just this, just this.” And what is the meaning of all that stuff when it loses its significance? She smiled again and said, “makes you think, doesn’t it?” What occurs between hospice workers and patients calls into questions the standard paradigm of autonomy and control that many of us are used to having (Foster, 2007). The relational communication in the mundane, the moments, the silences, and the whispers distinguishes hospice as a human alternative to medical and curative based conceptions of dying. The philosophy of focusing on the patient as an individual doesn’t (Foster, 2007).

Communication in hospice occurs in the silences and simple activities of life. It fosters listening over judging or imposing values onto patients and their families. Mission and improvisation overrules agenda-setting. The implicit principle that centers on the patients’ needs adapts communication to the patient’s worldview and preferences (Foster, 2007).

Many believe the contexts in which care is delivered and the barriers to “good” care contrast starkly with to that of a clinical or curative setting. But how, in practice, do
providers listen to each and every individual passing through a palliative care unit, in-patient hospice, out-patient hospice, or bereavement agency? Can systems of care actually be developed for something so personal as end of life? Can death really be tailored according to personal preference? Would we want that anyway? Can our old – and often standard – models of funerals represent the complexity and extra-ordinary nature of human life (Walter, 1994)?

These questions matter for a philosophy of care whose primary goal is treating each person as an individual and respecting the feelings, beliefs, and wishes of the dying person. Cicely Saunders, the founder of the modern hospice movement, envisioned the communication between hospice workers and families as one of dialogue, an explicitly “I and thou” relationship (Bradshaw, 1996; Buber, 1970; Foster, 2007). Buber himself argued that true dialogue is limited within an unequal “helping” relationship, such as the volunteer-patient relationship, and tends to be minimal when it does occur (Foster, 2007). The conception of communication has been used to describe how language shapes relationships at hospice through specific interaction processes.

Dialogue, for Buber, is relational and responsive, and an interaction process that underscores how talk is an essential building block of community at a place like hospice (Foster, 2007). His philosophy of dialogue depends on how the self interprets the other, or “thou.” Buber is not suggesting by “thou-ness” that every relationship should move toward intimacy and the disclosure/realization of the other’s real self, but that the “realness” of the other resists fixation or a closure of conversation. Every interaction holds the possibility of closure or new meaning. Dialogue is a process used to explain how patients, families, volunteers, and providers engage differently around end of life
(Foster, 2007). And in so doing, communication becomes productive, creating something new together as opposed to reproducing with either one has or is.

The ability, then, to achieve the ideals of dialogue are both facilitated and complicated by the practice of multidisciplinary teamwork in hospice consisting of nurses, physicians, case workers, dieticians, chaplains, and bereavement and activity counselors who all inform and influence care team goals and decisions.

Seale (1998) identified the emergence of dialogue as part of a larger movement toward patient-centered medicine and away from clinical medicine, which had made the voice of the patient less relevant. Achieving this form of communication, however, requires responsibility, responsiveness, and accountability. Improvisation, for example – something that is embraced – demands a high degree of skill and familiarity with the context and the role one is playing, and enough confidence to surrender to the moment (Eisenberg, 1990; Weick, 1998). One study, for instance, about active listening was ranked as the most frequently implemented nursing intervention used to “enhance and support the spirituality of clients and their families” around hospice care (Sellers & Haag, 1998, pp. 347-348). This model of communication, however, is both difficult to implement into practice and has received its own critiques as Walters (1996) states rather poignantly:

On the one hand, they [hospice workers] are committed to letting patients live as they wish until they die. On the other hand, hospices have a very clear idea of ‘the good death’…These are the two classic strands that together make a revival: a late-modern/neo-traditional attempt to promote a particular idea of healthy dying, and a postmodern enabling of individuals to do it their own way. (p. 89)
Therefore, a tension increases between encouraging the patients’ autonomy and remaining nondirective while advocating a “good death.” Even more, providers are encouraged to negotiate between the directives of the organization, the patient’s wishes and their own values. This balance is learned not through intellect, but through experience (Foster, 2007). Hospice workers are not change agents. Rather, they bear witness, support, and comfort the individual and family physically, emotionally and socially (Foster, 2007).

Hospice care, like emergency care, focuses on language, the body, and negotiating endless tensions and wishes. Human bodies are undeniably mortal and it is the symbolic constructions, the words – that ward off senses of mortality and extend the human body toward life (Becker, 1997). Since language has come to disassociate bodies from mortality, language has also become the power families, patients, and the public turn to at the hour of death and also what providers turn to when coordinating care around the end of life (Foster, 2007). Yet simply focusing on thoughts and words overlooks how our bodies and emotions are also dependent on our access to certain discourses (Seale, 1998).

Caring for bodies and emotions through language, improvisation, and relationships is a central goal of both hospice and palliative medicine. It is about relieving patients’ suffering – at the end of life (hospice) and during the entire course of serious, advanced illness (palliative medicine) – while also maintaining quality of life for them (Ragan, et al., 2008). The focus is on patients’ comfort and physical needs and on their emotional, social, and spiritual needs. The health care approach is patient-centered, as
patients are able to dictate what they need and want during both critical illnesses and in their last days or weeks.

Studies of talk and language are where actual and possible forms of organizing are defined and contested. The ways we represent our lived experiences and relationships to ourselves and our existence begin to unfold (Broadfoot, 2003). Understanding talk is also a way of understanding discourse and our access to them—how individuals perceive, think, and talk about emergency departments and hospice. Communicating at a time when life consists mostly of loss, the silences, the whispers, and the utterances of daily life become paramount. Because the languages and experiences of an emergency department and hospice remind us how much we take for granted, they remind us how much we can be moved by the words and stories of others. Even more, stepping into these worlds of unique discourses, interconnected concepts, revealing expressions, and stunning statements illustrate how subtly their talk frames and influences how people understand and act in the face of life and death.
Chapter 4: Communication and Dying

Interaction is dynamic. And language, meaning, and experience are at the root of many of the problems faced by dying patients and their families (Hickman, 2002). We are all influenced by other individuals, organizational structures, media and cultural environments. Therefore, rather than plodding through a boring and standard literature review about the ways communication has attended to issues around health, I am going to describe where and how I am drawing insight from specific literatures.

Communication issues are central to discussions about how to improve care for people who are dying. Dying can be gruesome, lonely, mechanical, and disrespectful. Contrasted with a romanticized view with loved ones by the bedside, patients are now often surrounded by busy nurses, interns, residents, lab technicians or researchers who are strangers, mostly because they discuss the value of our life in a language that makes sense in their world, a language different from those who are dying.

Like patients, physicians struggle to balance straightforward communication about terminal illness. They, too, have their own fears of getting sick or know someone who has been sick. They must also be sensitive to timing, sensitive to patient preferences, and sensitive to the accuracy of their prognoses. Above all, we ask that they offer some kind of hope, even if hope is oriented to maximizing quality of life rather than extending it (Wenrich et al., 2001). Dying and attending to the death of another person can present communication challenges for everyone involved.

First, I will describe the insight I am taking from an interpersonal approach to better understand the relationships between provider and patient. Second, I will describe
the knowledge I am taking from a social constructionist approach that challenges the idea that our experiences and meanings are not our own; rather, they are endlessly produced and made. Third, I will describe what I have gained from a critical cultural approach that takes the idea that our experiences and meanings are not only produced and made, but they are shaped within particular contexts. Therefore, the latter half of this chapter will describe how a critical and dialogic approach to understanding the consequences of talk is most useful because it allows me to see and think differently in regards to the ED and hospice. First, I shall describe the insight I am taking from three areas – interpersonal, social constructionism and a critical cultural – to explain the dynamics of communication and therefore the dynamics of clinical interactions.

The medical encounter has primarily been studied as an interpersonal communication event (Street, 2003). Specifically, it has focused on patterns of interaction between provider and patient and the nature of their relationship. Understanding the medical encounter interpersonally means enhancing providers’ and patients’ ability to make useful and thoughtful communication choices in practical clinical situations. The term “useful,” refers to developing choices that enable patients and providers to accomplish their own care goals, as well as make future clinical interactions more possible.

Because talk is almost always between a provider and patient or provider and family, medical talk is an interpersonal activity. Therefore, an interpersonal approach allows me to start thinking about what providers and patients need to know to interact productively rather than reviewing what we already necessarily know. This shift in focus
allows us to understand communication more as a process instead of a simple transmission of meaning.

Communication is a process that develops in response to a variety of conflicting goals. Patients and providers enter the medical encounter with specific goals in mind and throughout interaction, are endlessly negotiating these goals, or literally working through them together. And clearly, interactions can be of value, meaning that interactions are productive and open, or they can be of waste, meaning that interactions are reproductive and closed.

Developing skills for communicating about end of life is nothing new. In fact, developing skills has gained considerable attention with the help of the multicenter SUPPORT study (1995). This study demonstrated devastating problems in the care of seriously ill hospitalized patients. Specifically, it revealed that only 47% of physicians knew when their patients preferred do-not-resuscitate status. More, this study illustrates that communicating preferences regarding resuscitation is a challenging and important task for physicians (Chittenden, Clark & Pantilat, 2006).

Understanding patients’ wishes at the end of life allows clinicians to provide the type of care patients want to avoid in unwanted interventions, and to promote dignity and autonomy among patients (Chittenden, et al., 2006). Because of the dynamics of providers’ and patients’ interactions, much health research has been more focused on developing mass communication style messages where meanings are believed to be able to be packaged for the masses and sent off. But what we need are interpersonal communication style messages, especially around communication at the end of life. Understanding the medical encounter as an interpersonal event moves us beyond simply
thinking that the encounter is a face-to-face monologue to one where there is dialogue, or a genuine effort and curiosity to understand the other through trust and openness.

An interpersonal model of communication provides an important perspective on the dimensions of coordinating care around end of life. However, this view of communication often falls victim like most in the western world because communication here is understood as the transmission of ideas from a patient (i.e., sender) to a provider (i.e., receiver), or simply about the exchange of messages, or what one person says and the other hears. Unfortunately, this specific understanding of communication often does not serve us very well in a highly mediated, pluralistic, and interdependent world (Deetz & Radford, 2008). Studies that understand the medical encounter as an interpersonal activity often offer a set of skills and in some cases, very good ones. But to continue exploring the dynamics and consequences of talk, I have also gained insight into the ways in which medical encounters are also produced, made and affected by the contexts in which they are situated (Street, 2003).

Therefore, gaining insight into the ways providers and patients can interact productively with sensitive interaction skills is critical. Part of choosing more productive options in interpersonal interactions also means I pay attention to the gaps in current patterns of talk. These spaces and gaps include drawing attention to the way we form our experiences of life and death. More importantly, shifting to focus on these gaps and spaces is a way to begin to understand how meaning is constructed and contested through interaction. Therefore, I have gained significant insight into the ways in which our clinical interactions and meanings about life and death are produced and made and why this understanding matters for this project.
Social Construction Approach

A social construction approach to communicating about end of life issues provides awareness to more interesting processes of communication today – how social meanings get produced and reproduced through our patterns of interaction.

From a social constructionist perspective, I take the ideas that no word, action, behavior or event has meaning without understanding the larger meaning system in which it is placed. For example, the ED has been produced and reproduced through popular television shows. As a result, it is difficult to think of the ED differently from the larger system of chaos, blood, tempo, and dramatic romances between providers and patients. And therefore, death in the ED becomes difficult or even impossible to understand as something other than beeping monitors, IVs, bags thrown on the ground and sheets ripped off the bed in order to save a life. Believing that no word, action, behavior or event has meaning without larger context of meaning also means I pay attention to the way language about death and dying carries historical and often hidden cultural values and perspectives of which we are rarely aware. These values condition us to act in specific ways that influence what we believe to be true about life and death. Our beliefs, in turn, become socially produced and reproduced through our interactions. These social ways of interaction become habitual speech patterns without us ever questioning how or why we accepted them.

To say that values and language influence who we are and what we hold to be true, right and worthy of pursuit, is to say more academically, that language shapes our reality. The notion of reality as a social construction has infiltrated recent research in the social sciences where sociologists Berger and Luckman’s (1966) discussions of the
concept gained considerable traction. We, for example, act on knowledge that we’ve learned and accepted through things we’ve read about death and dying and developed our communication from other scholars’ research on death and dying. Other experiences that we learn from TV, songs, or media give us other ways to understand life and death. These accepted forms of knowledge based on socially constructed meanings, shape our understanding of life and death and thereby influence what we believe in and take to be true and right.

Retaining the idea that language shapes reality obviously leads to theories that our understandings and meanings of death are inherently constructed (Charmaz, 1980; Seale, 1998). Specifically, Charmaz (1980) asserts the following:

Any sociological exploration into the social reality of death must come to grips with values. Whether values are fixed and stable within a group or are open to reinterpretation, they give rise to the construction of the reality of death. Put simply, death does not occur in a vacuum. Rather, it is a dimension of human existence shaped by values. In particular, I submit that values built on the Protestant Ethos still have a pervasive but subtle effect on death and dying although cultural diversity and biographical experience may give rise to other effects. In that sense, values not only give rise to meanings of death but also to the everyday practices through which death is handled. (p. 12)

My own values about a good life, a good death, and good medical care have shaped and been shaped by my own experiences in health, death as well as what I have experienced in the ED and the hospice.
Experiences of health, illness, and death generate a collection of statements, or discourses, about what is possible for us to know, to do and to be when we walk inside a hospital or hospice as patient, provider, family or visitor. Understanding the medical encounter as a social construction, I share a similar commitment to the way discourse and language in medical settings act to perpetuate the interests of some people over others.

Although many of us can agree that some human bodily experiences are universal, such as pain, health and death, social constructionism argues that such experiences are subjective and understood according to the historical and cultural settings in which they take place, such as EDs and hospices. But in these particular settings, understanding how meanings are produced cannot fully be articulated without considering the ways meanings are shaped within distinct cultural contexts (Lupton, 2003). Therefore, I have also gained insight from a critical, cultural approach view of communication because examining the cultural dimensions of medicine and talk sheds light on why medicine and death is “characterized by such strong paradoxes, why issues or health and illness are surrounded with controversy, conflict, and emotion” (Lupton, 2003, p. 2).

Critical Cultural Approach

Another dialogic approach to understanding talk is a critical cultural view, overly political in its explanations by questioning how economic, material, and historical factors shape a culture’s responses to and concepts of health, disease and treatment decisions (Lupton, 1994; Lupton, 2004). For me, the term culture is not limited to the traditional anthropological definition. Instead, I understand culture as a way of life including ideas about treatments, beliefs about health and illness, language used to describe the dying
process, the institutions we turn to for help, and structures of our health care system that shape how we think and feel. I also understand culture to be a range of cultural practices, including artistic formations about the body and disease, architecture, including the physical and material spaces of hospitals and hospices, and further yet, our everyday choices and activities that are in line – and orient us towards– a particular culture.

Moreover, and of particular interest for this project, is the struggle defining and naming health, illness, and death. This approach to defining and naming is not only a state of physical or emotional being. Instead, it controls the resources we have available to us to sustain and promote life, like medicine, food, water, shelter, knowledge and so on. Note that through the struggle of naming and defining comes tension and conflict over the ways things are. And in a perfect world, this struggle produces choice. That is, a choice to get a constructive discussion going in places where none seems needed.

Of great interest then is the way language forms relationships but in doing so, sets distinctions about life, death and medical care. For example, I have struggled to name health, disease, and death. What is acceptable for me to say? Should I say “passed” around my family, “died” when I am in the ED and use a combination of both when I write so as to not offend my audience? The language we use about death bespeaks a society struggling to figure out what to value. Even more, it struggles over different systems of valuing, which naming puts into play. Therefore, the critical culture approach engages in a struggle to try to develop alternative languages of medical care and death. Doing so requires difference in the way language is used and the relations and distinctions it puts into play for our understanding of life and death.
Instead of focusing on the individual, a critical cultural approach centers on critiquing the social conditions under which individuals act in regards to medical care. A turn to culture exposes the complexities and contradictions of what a culture does or does not do (Treichler, 1990). Specifically, questions of death are significant in a culture, and significant changes in dying patterns often signal broad cultural change. Even more, “whatever else a culture does or does not do, if it wishes to reproduce itself, it must produce new members” (Treichler, 1990, p. 113). This idea sheds light on the intersection between culture and medicine.

I have adopted great insight from Treichler (1990) whose account of medicine and the construction of childbirth paints a wonderful example of the intersection between culture and medical discourse. Her study begins with a cultural “crisis.” The term “crisis,” however, is used conventionally to mean a turning point in a sequence of events after things get better or worse. Further, she illustrates how childbirth patterns, like dying patterns— in the U.S. are disrupted at many levels: legislative battles over who can legally deliver babies, malpractice and other forms of litigation, rising insurance rates, and health-care costs, lobbying contests, and market competition (Treichler, 1990). She explains that “these disruptions are played out in language, they embody the tensions and contradictions of the health-care system and the culture in which they occur” (Treichler, p. 115). These tensions also bespeak of what a culture is trying to value around health. And if a culture does not want to reproduce itself, it must teach its members to think, practice, relate, and know in new ways.

Her study generates a host of questions about childbirth that are equally relevant for death. For example, where should death take place? Who is best qualified to supervise
and pronounce someone dead? Who should decide? How should pain be managed? Who should profit from it? How much should death cost? Who should pay? Who should be paid? In a society as pluralistic as our own, positions and meanings should also be as diverse. But for the most part, meanings remain the same and become reproduced through interaction until a crisis arrives, or a perfect storm. Crises and storms, however, like those surrounding medicine, society and economics, often offer a turning point where the negotiation of meaning are contested even in subtle ways, thereby calling into question widely accepted practices and assumptions around dying. Even more, “a crisis that continues long enough may at last destabilize established views of reality” (Treichler, 1990, p. 118). I am not arguing that death is in a crisis, however. Rather, and in line with Treichler, I am arguing that the crisis is not about death per se, but the meanings surrounding death that are produced and reproduced through the way we talk and interact.

Again, the core of any crisis is meaning. What does death mean? To whom? And under what circumstances does a given meaning about death come to constitute an official definition of our experience of it? For Treichler (1990), the problem of traditional childbirth is rooted not in “medicalization” but in monopoly: monopoly of professional authority, material resources, and linguistic capital. That is, the power and access to establish and reinforce a particular definition whether it is over childbirth or death. For example, death in the U.S. often takes place in hospitals because a definition of death as a medical event is so strong that it determines the material location of it.

Of interest to Treichler (1990) as well as this project, is the way some meanings come to function as official definitions within a culture. Specifically, it is not about which
definition is used, but the process by which definitions are constructed, implemented, and reproduced. Even more,

It is quite plausible, in terms of meaning, to say that multiple meanings may co-exist in a culture—even in a single room or in a single head. But a definition is much less democratic. It sets limits, determines boundaries, outlines. Unlike meanings, which are bound up in what people think and have in their minds and intend, definitions claim to state what is. A definition is a meaning that has become ‘official’ and thereby appears to tell us how things are in the real world.

(Treichler, 1989, p. xii)

Definitions around death and dying are outcomes of struggles and crises, however. Therefore, they are also unstable, negotiated, and often temporary (Treichler, 1989). Consequently, proposing a more complex understanding of how definitions of death and dying are created matters. This complexity illuminates the ways language shapes our meanings around social arrangements around dying, professionalism in the clinic, economic resources for treatment, and political activism around new measures surrounding health care and dying practices.

Medical definitions, much like any culture’s definitions, determine actual practice and structural arrangements like the physical space of hospitals and hospices and our access to them. Definitions also determine political and economic policies and practices, including standard protocols, insurance rate, reimbursement, time providers must work, and time spent with patients. Focusing on the construction of definitions as a complex cultural practice, however, seems difficult or out of place in settings that need to rely on truth, standards, protocols, and consistency. For even in talking about the construction of
language, discourse, and definitions often generates an admiration for returning to clarity or certainty about is real. And the real is always linguistic and political, as well. Therefore,

A definition is not, as conventional wisdom assumes, the set of necessary and sufficient conditions that constitute a known, fixed starting point for political, economic, and ideological struggles. Rather, a definition represents the outcome of such struggles—an unstable, negotiated, and often quite temporary cultural prescription (Treichler, 1990, p. 120).

Definitions provide clear prescriptions for directing laws, polices, and everyday practices around end of life. If a culture wishes to reproduce itself, it must produce new members who in turn, reproduce the same language and definitions (Treichler). Comparatively, if it doesn’t wish to reproduce itself, it must produce a crisis, a turning point, that calls into questions even widely accepted practices, assumptions, and ways of talking about death. This move focuses more on the way people talk thereby influencing polices and practices rather than focusing on who is talking. People aren’t the problem; the way people talk is the problem. This distinction is important for understanding culture and its dynamic and sentimental relationship with medicine and language.

Understanding culture around end of life communication includes focusing on discourse and the way that the use of language in medical settings constitutes relationships as well as distinctions about what we as a society value. Therefore, an understanding of language in both written texts and talk is the primary site of struggle over where meaning is produced, how it is produced, and by whom it is produced (Deetz, 1992). Out of the struggles among competing discourses comes tension and the resulting
choice to reproduce something we already have, or produce something new and different
(Lupton, 1994). Such an approach recognizes the importance of the discursive and
linguistic processes by which patterns of illness, health, and death are shaped and
perpetuated by our very own talk that is endlessly shaped within particular cultural
contexts like an ED and hospice.

Understanding the role of culture in the organization of end of life care as well the
construction of it matters for our ability to question the existence of essential truths. This
doesn’t mean it is necessary to abolish essential truths about death and dying. Rather, it
asserts that “truth” should be considered the products of tension-filled relations and as
such are never neutral but always acting in the interests of someone (Deetz, 1992).

Examining discourse within clinical settings has helped me to understand how
cultural contexts shape our identities, our feelings, and emotions. Because according to a
critical cultural approach, these, of course, are largely discursively produced experiences
that are incredibly dynamic and complex. Since discourse, language, and meaning are so
central to this study, the consequences of the way we talk as well as identifying where we
struggle in our talk is central. Therefore, I can take even more insight about the
consequences of our talk within cultural contexts by borrowing insight from a dialogic
perspective that takes understanding and critique as part and parcel for understanding the
consequences of talk through interaction. Even more, a dialogic perspective offers a way
to describe the following: intimate and complex relations between medicine, culture, and
discourse. It also gives us a way to describe the ethical questions of how we should
behave, to who we truly are, and what we should do as individuals, professionals and
institutions around end of life (Broadfoot, 2003).
Critical and Dialogic Perspective

A critical and dialogic perspective has much to offer this study because it exposes the ways discourses are implemented, negotiated, and transformed with health care providers in EDs and hospices, and patients, families and friends. In short, this perspective focuses on the way people discursively construct and contest what it means to be healthy or terminally ill in the 21st century. First, I will describe what I gain by taking a critical approach. Second, I will explain the insight I take with a dialogic approach and finally, I will outline why using both approaches will shed light on the messiness of clinical life.

Critical approaches start with the basic ontology that our perceptions constitute our realities as we attach meaning to experiences and events and that these meanings arise through interactions (Alvesson & Deetz, 2000). Therefore, they also start with an epistemological assumption that we come to agreement about what is real intersubjectively. An epistemological assumption is concerned with questions about “how do we know, and how can we come to know.” For example, different people approach the end of life and make decisions about how they want to die differently. Some may want to have all the facts and data about their disease and want to know exactly how many days they have left to live. But these same people might be moved so much by a story of someone’s experience with the disease or their own preference for dying. The story, then, becomes a different way of knowing and a different way of orienting towards end of life.

Therefore, to say that we come to agreement about what is real intersubjectively, is similar to the belief that others understand and know what we are going through and vice versa (Pagis, 2010). Because in everyday life, and without always being aware it,
“we tend to live a big part of our lives in other people’s minds” (Pagis, 2010, p. 9). As a result, we often take on these other ways of knowing as if they were our own, and as if they were our only options. Therefore, a critical approach sheds light on how we often unknowingly accept routine practices without critical examination to preferred ways of knowing and thinking. Even more, a critical approach underscores the processes by which we come to agree on a shared experience and a shared feeling of what it is like, for example, around the end of life.

For this to occur, critical approaches are unique insofar as they challenge dominant discourses, or dominant ways of knowing, in order to get better discussions going in places where none seems needed (Alvesson & Deetz, 2000). And a place where discussion is strained or avoided is around death, and our preferred ways of dying. A goal, then, of critical approaches helps to bring topics like death back into discussion. In doing so, a critical approach helps generate more discussions and thereby include more voices around end of life. Incorporating more voices matters for developing new understandings rooted in cultures that can define experiences through a vocabulary that they helped to create. Further, this way of interacting acknowledges difference through genuine listening, understanding and willingness to be changed, especially in interaction with others’ experiences, meanings, and languages that are different from ours (Deetz, 1992; Zoller & Kline, 2008). Similarly, this open, communicative attitude is a goal of a dialogic perspective, which helps me understand further yet the dynamics of talk in the ED and hospice.

A dialogic approach seeks to inspire a discussion where none seems to exist, albeit differently from a critical approach. Specifically, in order to generate more
discussions and have different voices included in defining experience around end of life, a dialogic perspective sees interaction as an endless struggle (Alvesson & Deetz, 2000). Even more, a dialogic perspective helps me to see interaction as a site of struggle between diverse forms of knowing, being, and speaking in the ED and hospice. In so doing, it helps expose the multiple ways people discursively construct and understand death and dying as things endlessly accomplished through interaction.

Importantly, this model of interaction matters around end of life communication because within struggle, particular perspectives and voices are often suppressed in order to stabilize and provide shared meaning for participants. For example, if someone says they are not afraid to die, we often always assume they must be “death denying” since their story and perspective is essentially re-writing the meaning of end of life. For understanding end of life communication, the critical evaluation of these moments of struggle matters because these are the moments where individuals attempt to make sense of coherent worlds out of hidden and fragmented points of discursive struggle. For example, when I first started observing hospice, the nurse practitioner told me a patient had recently been admitted with monitors still attached to their chest from the hospital. She said,

When we admitted the patient, we starting removing the monitors as the patient interrupted and said, ‘Wait! How are you going to monitor me without them?’

The nurse paused being struck by the question and said, ‘we monitor you here with our eyes.’

This example illustrates the struggle over understanding what being a hospice patient is like. For the patient, it made sense to have monitors attached to receive the
proper care. Comparatively, the nurse practitioner struggled to define hospice experience as something other than having monitors attached to a person’s body. In fact, monitoring patients with their eyes challenges other understandings of medical care at the end of life that is often thought to include monitors, IVs and other equipment.

Together, a combined critical and dialogic perspective gives a distinct understanding of the dying experience. Even more, it reveals many ways that communication fosters particular meanings about death and dying as the patient and nurse practitioner illustrated. This type of understanding moves beyond “thick descriptions” (Geertz, 1973) that is characteristic of an interpretive approach to actually asking researchers to take an ethical position with regard to the implications and messiness of communication, and their role in the mess. Therefore, distinguishing between interpretive and critical approaches will help you, the reader, better understood the goals of this study as well as some of my commitments. I borrow from Deetz (2001) a useful way of distinguishing between both approaches by describing the concepts of consensus and dissensus for understanding talk and the consequences of it in the ED and hospice.

According to Deetz (2001), scholars orienting near the consensus pole seek order and commonality. They treat order production as a dominant and natural feature of interaction. On the other hand, critical scholars like me consider struggle, conflict, and tensions to be a natural state for understanding interaction (Zoller & Kline, 2008). Instead of focusing on describing and understanding realities, I am focusing on the dissensus pole because I challenge dominant ways of knowing in the ED and hospice in order to uncover and reclaim hidden conflicts embedded in clinical talk. Therefore, my approach is rooted
in voicing and acknowledging difference that helps bring a relational focus to a field often focused on message production. In short, my focus is towards the ongoing interaction where meaning is negotiated and produced within cultural contexts. As a result, I share an enduring interest in discourse, praxis, and language and the opportunities they hold for inspiring discussions around end of life, helping to position us differently towards interactions with the ED and hospice.

Language is central to this study because it positions us to look at and respond to the death in a particular way by forming relationships and distinctions, as well as making some things thinkable and discussable and others not. This “positioning” is more than just having a set of beliefs or attitudes about health and illness, though. Language, in fact, positions us to look at and respond to health and illness in a particular way (Deetz & Mumby, 1985). Therefore, a critical and dialogic perspective has given me tremendous sensitivity to how language is core to the process of constituting meaning around life and death, rather than simply naming what they are.

These sensitivities begin to bring awareness to how language and discursive formations control and prevent us from acting, thinking, and saying something else about life and death. Furthermore, they bring awareness to how the “particular ways of drawing on discursive formations as well as challenging and protecting them are all accomplished in actual interactions” (Deetz & Radford, 2008, p. 191). In other words, it brings awareness to the ways we struggle in interactions around end of life.

I have spent considerable time describing the ways in which meaning is produced. Next, I will describe what happens to meaning production when struggles persist and our talk becomes distorted. That is when language closes communication or prevents
discussions from taking place. Even more, shifting to the ways discourse becomes distorted is useful for understanding a subject like death, a subject we don’t talk very much about. Therefore, this next section will outline specific ways our talk leads to distortions, as well as ways our talk may always begin holding open important opportunities for communicating around end of life. Moving from the consequences of our talk to the opportunities it may hold is similar to thinking of the two options we have when we speak: we can talk to tell or we can talk to learn (Deetz, personal communication, 2008).

Discursive Opening and Closing

To say that communication is the language of structural and system preferences is to also say that procedures, policies, practices, and even preferred ways of being become unable to be questioned or discussed (Deetz, 1992; Thackaberry, 2004). Therefore, I follow critical studies that argue distortion is an evitable part of contemporary life.

According to Deetz (1997), a key to identifying and addressing discursive closure is examining interaction practices that privilege certain interests, meanings, and vocabularies over others. Specifically, I borrow from Deetz (1992) who outlines eight ways discourse becomes closed: neutralization, naturalization, subjectification of experience, pacification, topical avoidance, meaning denial, legitimation, and disqualification, many of which will be developed later. These moves distort communication by suppressing “the unseen conflict in ways that appear to address the issues rather than suppress it” (Deetz & Radford, 2008, p. 191). More often that not, we use these strategies, and they use us, consciously and unconsciously. Because certain
forms of discourse act to distort power relations, disguise inequity, and discourse and language has the ability to oppress as well as emancipate us, and our experiences (Clair, 1998). Said differently, communication can be silencing, especially around death and dying. To understand the dynamics of how communication becomes distorted and how communication silences, I borrow from Clair (1998) who asserts,

Recognizing that discourse does more than communicate, realizing that discourses also articulate grand social systems, and discovering that discourses can silence certain people, specific issues, and particular interests, demands our attention. Of course, we need to continue exploring how communication silences, but we also need to explore how silence communicates. (p. 39)

Therefore, the narratives we live about life and death may speak of certain conditions while disguising others (Deetz, 1992). And some stories surrounding life and death may be expressed while others are sequestered (Clair, 1993). Further, the issues of power, culture, politics, aesthetics, and economics are all ways of explaining how language opens, closes, and distorts communication as well as how words and speech organize silence. The following example illustrates how communication becomes closed when established procedures at the end of life come into contact with a different culture whose access to language is distorted through a number of ways.

“Okay, let’s go see this thing that I don’t agree with,” doc says.

“Okay, but what’s that?” I ask.

“The older woman who recently came in on the stretcher, the 95-year-old female from Russia.”
My reflective experience: Getting closer to the room I see the 95 year old with a mop of white hair, eyes shut, head tilted to the right and a breathing mask around her mouth that strapped behind her head and a large clear tube connecting the mask to the machine helping her breathe. In a gray gown that was only visible above her chest and otherwise covered in a white hospital blanket I thought “oh no” as we walk in.

“We have all the info we need,” doc tells the nurses. Holding the chart, doc walks towards me and says,

“Look at it and tell me this doesn’t seem absolutely ridiculous.” The EMTS start gathering their things and say,

“Oh yeah, and she speaks 100% Russian. Absolutely no English but responds to pain and her name sometimes.” Still trying to figure out what the chart says, Doc takes it back and says,

“95, DNR, needs a new G tube to help her eat and drink. Can’t speak English, pretty non-respondent. I would never make my family go through this.” Doc looks at the EMTs and asks,

“When was the last time she has had fluids?”

“We think Friday,” they say. And today is Monday. Shaking her head Doc says,

“Friday! Food is one thing but with fluids she could die,” doc says. I look at doc and say,

“So she is DNR but without the tube she would die?”

“Well, she wouldn’t be able to eat or drink so eventually yes,” doc says.

“And food through a g-tube means a sandwich or apple sauce?” I ask. Doc laughs and says,
“It depends but more like the latter.” How is this DNR I am thinking as we walk into the patient’s room.

“Marlice! Marlice! How are you?” Doc says. No response as doc walks closer and touches her arm. The patient turns her head slowly and opens her eyes but looks uncomfortable and exhausted. Doc keeps talking and rolls down the blanket and lifts her gown to expose the g-tube. Doc takes her stethoscope and begins moving it around her belly pausing to listen. Marlice looks like she has fallen back to sleep. Still touching her belly with her bare hands, Doc looks up and says,

“It seems to be working just fine.” I look at doc and ask,

“Can you ask her again if she wants this done?

“What do you mean?” Doc asks.

“Well, once something is decided can you ask them again?”

“Like being DNR?”

“Yeah. I mean this seems complicated if she is DNR when essentially she would die without this artificial tube.”

“DNR is what I wish everyone would be! Unless of course someone like you who is young and healthy – we’d do everything we could. But DNR is the gold goal that I wish many would choose at this stage. So no, once the chart says it, I do what I am told and being Russian, she has strong cultural values about what to do.”

“Crazy situation. So can you fix it or does someone have to come in?” I ask.

“Well I am going to put some fluids down to see if it is working properly first.”

I take several more looks at this 95 year old who is essentially helpless, completely voiceless without fluids or food for 3 days who is here to have her tube fixed
so she can drink and “eat” again. Doc is already at the computer as I stand outside the room for a minute longer pondering over this disturbing situation. I walk back to the computer where doc is reading the patient’s records and looks up and says,

“She has been in a lot and just five days ago they took a CT scan.

“Why?” I ask.

“Guess they wanted to check her belly.”

“So without speaking English and a little unconscious, do you need to ask her for her consent?”

“Ask whether she wants one?

“Yeah.”

“No, we love scans here.” I looked at doc and slowly walked back to my post totally disturbed and confused. Doc walks over and says,

“I have an idea. Do you like coffee?

“Yeah.” She grabs her wallet and we walk to the café passing the 95 year old. I ordered a coffee and doc ordered a raspberry scone. We walked back and I said,

“What would happen if you didn’t fix the tube if you didn’t believe that was ‘right?’”

“That would never be an option. And I feel bad we are doing anything in the ER.”

This interaction illustrates how distortions emerge at different moments of the interaction and can be cultural or systemic, like an institutional practice, or a suppression of a conflict closed off through language. Specifically, choice gets suppressed through both institutional regulations as well as cultural values in this interaction. Doc said, “once the chart says it, I do what I am told and being Russian, she has strong cultural values
about what to do.” Both the institutional practice of charting and the values embedded in a Russian culture prevent a discussion from taking place and furthermore, close off any decision and course of action from critical engagement. The patient arrived unable to speak English and was pretty non-respondent. However, her previous chart listed DNR. Therefore, care practices and care decisions were already decided before the patient arrived thereby influencing what the doctor could and could not do for taking care of her. Even more, these practices closed communication further since the patient could not verbally respond. Communication then, which is “open,” refers to the ability of patients, families, and providers to question sediment procedures, meanings, practices, and even preferred ways of knowing around care.

Therefore, this study will continue to understood how discourse, language, and silence organize meanings around end of life and how decisions with significant social, economic, political, physical, and emotional costs are coordinated around end of life. This focus takes language and struggle over meaning seriously. For it is through interaction that unfolds the complexities of how end of life is organized and in whose interests is it being organized.

Specific Research Questions

Scant attention has been given to qualitatively describing the day-to-day emotional issues of patients, families, and providers and the interactions that make these issues come alive. The literature begs for an understanding of how communication and care are composed and organized and what discursive openings and closing are present and possible at the end of life. Therefore, my specific research questions are as follows. First, what is the nature of talk in the ED and in the hospice? Second, how do providers'
own work practices impact talk and how does talk impact these same practices? Third, how do these practices shape a particular orientation toward life and death? Finally, how does the talk in both environments enable and constrain providers' ability to make choices around the end of life?

It is important to note that I have taken a multi-layered approach in order to answer these questions. The first two questions require an ethnographic account of what took place. While the second two questions require me to move beyond simply understanding the dynamics and consequences of talk, to an actual critique of the way talk is organized at the ED and hospice. In doing so, this multi-layered research approach has allowed a much deeper understanding before being sensitive to the way talk creates openings and closures within these settings. The following chapters will outline the methods and background of this study including my approach to a multi-layered approach to fieldwork and the tremendous ethical work that is demanded within the ED and hospice.
Chapter 5:

Methods and Fieldwork

I find entering clinics, especially EDs and hospices, very difficult. In part because they are filled with indelicate odors, sights, and sounds and because they are places where sick and not so sick bodies are overworked, overstressed, and underappreciated. They are also sites that cut to the core of who we are; what it means to be a patient; what it means to be a provider, and the role we must play and the skills we need to perfect that role. In essence, they tug, pull, and pound on our hearts and souls in the name of healing and ask questions concerning the meaning of life and the meaning of death. My project is not intended to be a generalizable account of all hospitals and hospices. Rather, it is intended to demonstrate concrete processes by which language, discourse, and culture work in settings as delicate, dynamic and emotional as an emergency department and hospice.

For these reasons, I have approached this project ethnographically, with minor variations as I saw necessary. My research questions are twofold in that they require two different sets of methods to understand first and then critique. This move, however, is risky around issues as sensitive as end of life. Given the nature of this study and the difficulty I have had with it, my approach to ethnography is a result of what I know, how I have been trained, and which approach is necessary and helpful to understand these sites.

I was trained as a four seasons ethnographer, which I believe is necessary for this kind of study in order to subject myself to be close to participants as we both experience life in the ED and hospice. I have also been trained as a critical and dialogic ethnographer, which I believe is essential for this study to be able to make sense and
explain the way the workers in the ED, the workers in hospice, and the way I experienced these places. The two approaches complement each other and are not distinct from each other. Rather, each has helped me to understand, learn, feel, and critique what I have experienced. Most importantly, each approach has sparked different sensitivities allowing me to see things I had not seen before. Both approaches, however, will be explained in great detail later in this chapter.

Writing this report will also bring a strong degree of sensitivity to what I heard, felt, and thought. In order to bring more sensitivity to these issues, you will hear two different voices that I mentioned in chapter one. The first voice is an insider who was at these sites trying to understand what was taking place; the second is an outsider looking back on these interactions and experiences and trying to explain them. Lastly, much of the latter part of this chapter will describe my ethical commitments that grew out of my actual interactions with these sites.

In the ED and hospice, I could not remain a coherent person constantly focusing on what people were saying, what I was seeing, what I was thinking, and what I was feeling. The experience was messy, complex, and crazy; just like these sites. But I also believe these feelings breathe life into this project’s perspective for the providers doing the work, and the patients and families receiving care. Let me begin here with an interaction I had that will help you better understand what I mean when I say that my approach to ethnography grows out of actual interaction with these sites.
Perspectives on Ethnography

It's 6pm on a Friday. The smell of disinfectant blasts my face as the double glass doors open to the main hospital entrance. I walk along the white tile splattered with grey flakes to a door on the west side with "emergency" in red written on top. I open the door. CNN is blasting from the TV and five or six patients sit in those uncomfortable leather chairs in the waiting room. I walk up to the desk where a nurse is seated. "Can I help you, she asks?" "Yes, my name is Carey and I am here to see Dr. Ryan." She immediately leans back to push a red bottom as the door opens.

"Go on back," she says.

As I walk through, I wonder what the people are thinking as I walk up to the front, dressed in street clothes and then straight back through the double doors. The monitors are beeping, red phone ringing, and a stretcher is being wheeled towards me as I try to find Dr. Ryan. I glance over towards the computer as she looks up.

"Hey, you made it!" she says. "Let me take your jacket; put your purse in with mine right here. Have a seat and make yourself as home. Do you want some water?"

"No, thank you, I'm all set" I reply.

Still catching my breath and trying to take in all that is happening, I hear,

"Hey Mead, this is Carey, she is a PhD student in communications from Boulder, studying end of life communications."

"Ahh, you've come to a good place – we're horrible communicators!" he replies and they both laugh.

"What kind of study did you call it again?" doc asks.

"Ethnography?" I reply.
"Yes, what the hell is that, some Boulder word?" she asks, and they both laugh again.

I look at Doc and say, "well instead of handing you a survey and watching you in a lab, I am observing you in your own environment in order to get a better idea of the big picture."

She smiles, "Okay, that makes sense."

I wonder how many nuances are lost as they translate medical jargon for me. I also think how important it will be to represent my project that accounts for these very nuances and that is accessible to audiences outside of academia.

This study is guided by ethnographic commitments to organization, communication, ethics, and fieldwork. I understand ethnography to be a written means of representing and presenting a culture by describing and understanding localized practices, particularly communicative practices. Further, understanding these practices helps me to uncover how talk produced and reproduced certain meanings, norms, and strategies around the end of life as well as is guided by these. Even more, I believe that to do ethnography is to subject myself, my body, my personality, my social condition to the set of circumstances that play upon a group of individuals so that I am close to them as they are responding to what life does to them. Encountering the sites in this way is not a simple light shift in perspective.

Rather, it is deep work that requires humility and vulnerability to acknowledge that how we have been presenting ourselves is not necessarily forthright and honest. Even more, this way of being close offers an authentic way of understanding who we are and what we are capable of doing. Importantly for this type of work, if I am not aware of
my many “shadows” that are hidden from expression, all of my work is affected, as well as all of my relationships with the participants as these sites. Shadow work requires vulnerability and humility to acknowledge that how we have been presenting ourselves is not necessarily forthright thereby offering a powerful potential of abandoning the shadow selves we’ve been performing in favor of a more “honest” expression of our selves. Shadows affect what I say about my experiences and how I write about my experiences.

Therefore, my approach to ethnography endlessly encourages sensitivity to the relational consequences of the way I write or represent my experiences. Representation does far more than communicate about a subject; it simultaneously creates these very relationships. Said differently, representation for me is tangled up in the way I not only tell the story, but also the story behind the story (Denzin, 1991).

The story behind the story occurred often when I uncomfortably oscillated in the field between a researcher, a professional, a friend, sister, a daughter, and a granddaughter. I was caught in between saying something I wanted to say like, “I am so sorry, I hope your dad feels better,” as opposed to something I “should” say based on my training and reasons for being there like, “thanks for letting me observe.” Furthermore, I was caught acting and doing things that aligned with “research and institutional ethics” like not crying, not running out of the room when things got too messy as opposed to reminding myself that crying, running out, hugging, and feeding someone are natural and sometimes uncontrollable behaviors. For these reasons, one specific story behind the story happened at hospice with Anna.

Anna, who was 96 and would have turned 97 the last day of July always looked like she was sleeping, and for that reason, didn’t have many visitors. I knocked hard on
the door every Friday knowing that interruption was necessary for her since she always looked pleasantly happy to see me, even if she didn’t want anything from the hospitality cart that I pushed around to the patients. One day, though, she surprised me and asked for vanilla ice cream. Her hands were small and crippled, as was her body. She hadn’t been out of bed since she arrived over nine months ago. I got a vanilla ice cream from the freezer and returned to her room. I pushed the button on the side of the bed to lift her up so she could eat. She shook her head while trying to re-adjust her back and head but she had hardly any strength and said, “these beds are so uncomfortable.” I tried to re-adjust the pillow but I agreed: they didn’t look comfortable.

I opened the ice cream and handed her the spoon and cup since before, she drank her coffee by herself, although slowly and unsteadily. She stared into my eyes, took the wooden-paddle spoon and put it lightly into the plastic cup that had very little ice cream on it when she took it out. Her arthritic hand continued to hit the side of her right lip, then the left lip while her toothless mouth tried to do a little work and catch it. She dropped the spoon in the cup. I knew volunteers weren’t supposed to help feed patients, but when she put the spoon down, she looked at me and softly said, “I need you to help me.” I smiled, sat down on the right edge of her bed and took the cup saying, “sure.”

No way was I going to tell her sorry I can’t, let me get a nurse. Should I have done that? Did I violate organizational volunteer rules? How could I tell Anna at 96 that I couldn’t help her eat this ice cream and that her condition is too severe and her body too fragile to have other people, like me, help? I took the spoon, filled it with some ice cream, and slowly began to feed her. I raised the bed a little more to eliminate any chance of her choking.
It was similar to feeding a baby or my two-year old niece: filling the spoon, finding the mouth and snap the lips go. Then, the mouth opens again for another bite. But Anna was 96 years old and she didn’t take her eyes off me.

After the fourth or fifth bite, she quietly said, “Never would I believe someone would need to help feed me ice cream.”

I said something stupid like, “every one needs help some time.” But inside, I was wondering what else Anna was thinking and what else she wanted to say. Inside, I was also wondering what it feels like for our bodies to be that weak and not have control to eat a cup of ice cream. Her mouth opened again for another bite.

That next week when I visited Anna, her son was there trying to wake her up by rubbing a Bud Light cold beer can along her forehead, but she didn’t budge. The following week, before pushing the cart, the volunteer manager reminded me how important it is not help feed patients who need “assistance” because hospice is completely liable. I assured her I wouldn’t do it again but also expressed how difficult it is to not help. She agreed and told me that Anna had been telling a few people that she is “ready to go.” I started near Anna’s room. She was awake and I said,

“Hi Anna, it’s Carey with the hospitality cart. How are you?”

“I’m ready to go,” she said. I took a big breath and softly said,

“I’ll miss you.”

And then I touched her bony shoulder and said so naturally, “I love you.”

“I love you too,” she softly said.

It was a brief, awkward, and never-forgetting interaction. Anna died the following Sunday. And for some reason, I felt so relieved and so happy that she had died
and didn’t have to live like that any more. But at the same time, it felt unbelievably wrong for thinking that and so I began to write about Anna. Fifteen pages later, I realized the multiple positions I am feeling, thinking, and writing based on my experience at hospice and the ED.

The ways in which we live and understand our lives and the lives of others depend on the kinds of access we have to different forms of discourse and language (Broadfoot, 2003; Weedon, 1997). For that reason, ethnography, particularly dialogic ethnography, remind me to focus on language and its powerful components in order to keep me sensitive to the ways I begin to construct images of people, the sites and events under study through the stories I tell, the relationships I am creating, and the ways I am presenting and representing this experience through writing (Taylor & Trujillo, 2001).

Further, a dialogic approach to ethnography encourages me to do several things in my study. First, it reminds me to participate and engage personally by being present and open to the body as a site of knowing. Second, it allows me to explore partial failures, misunderstanding, and awkward silences. Third, it reminds me of my role as co-performer in this study in order to understand the co-constructed nature of this type of work. And fourth, it allows me to consider reflection as a form of reflexivity questioning actions, images and desires as well as stories heard, told, and felt (Conquergood, 1991).

In essence, this study is guided by this general commitment to ethnography, studying social life in process, as it unfolds. But the commitments that guide the research process are more specific yet: they are creation-centered, align with the seasons of nature and exist in the spaces “between” (Gonzalez, 2000).
This creation-centered approach to ethnography is what I described earlier as a Four Seasons approach. I was trained in this way seven years ago. It is less an approach to ethnography as it is a way a life that affects the way I write and think. Like its name, the Four Seasons of Ethnography uses familiar research methods but does so according to the natural cycles, including spring, summer, winter, and fall (Gonzalez, 2000).

Specifically, the natural seasons as you know them reflect the natural cycles of fieldwork. For example, in the spring, we prepare our crops by tilling the soil and planting seeds. Similarly, in the spring, we prepare for fieldwork by gaining permission to our sites and doing some background reading. Summer rolls around and we hope for nourishment or rain for our crops and must remain attentive to the detail of their progress. In the field, summer is intense as we gather fieldwork, journal, interview, and begin to feel exhausted in the summer heat. Autumn arrives and we hope to reap what we planted and are often pleased but overwhelmed with the amount of growth, care, and cleaning up required. In the field, we are simultaneously pleased with our data but overwhelmed by it and not sure where to begin analyzing and how exactly to leave what has become an integral part of our lives. The frigid winter comes and shuts down the life process almost to a halt. We need to conserve energy for our crops fully aware that our success in the spring is determined by our previous year so we must make smart decisions. In the field, we, too, have taken shelter to write and rest. But the winter can be cold and lonely, making writing difficult because like our crops, we remember that we are the ones who are responsible for planting, preparing, nurturing, and representing the story to others (Gonzalez, 2000).
This ontology, or the things we may claim as the nature of something, assumes connection with the site and reflection as necessary to privilege awareness of the human instrument, or ethnographic researcher. Further, this ontology assumes respect for the unavoidable cyclic nature of emergent experience as co-creative of ethnography. The goals of this research, as well as my own, are texts infused with awareness that produce an ethnography that is holistic and dynamic (Gonzalez, 2000).

Accountability is of central importance to ethnography. Without honest accounting of my methods and decisions along the path of an emergent design, it is difficult to learn the nature of my work and my own assumptions (Gonzalez, 2000). Four seasons of ethnography does not eliminate conflict or tension; it reflects the experience of it. Therefore, the results are personally and academically tentative and dynamic. Like the circular progress of a spiral, the researcher and theories develop inductively and rhythmically, with no claims of absolute knowledge. Instead, the results are partial, multiple, subtle, and fragmented (Gonzalez, 2000).

Further, a Four Season approach is less about being immersed and more about becoming infused into a culture. In other words, it is less about plunging into a culture to absorb its meaning and more about being permeated with a culture so much as to be altered by it with a new sense of purpose. This shift allows me to be transformed through the research since my perspective is not just standing in a different place but seeing with a different set of eyes. These different set of eyes produced varying points of view about life, death, and medical care that help me develop thoroughly an ethical understanding of human experience. This approach led me to two specific settings and cultures.
Description of Research Sites

To assure rich data and to see medical talk, I chose two settings – Sage Medical Center and Hospice of Saints. These two sites provide emergency care and end of life care in Colorado respectively. The patients, families, and providers come from diverse populations with diverse forms of knowledge. Together, they exemplify the formal and informal contexts, language, and strategies for organizing care around life and death.

Sage Medical Center

Sage Medical Center (SMC) has been serving Colorado for 65 years, making it a well-known Colorado institution and landmark. SMC provides general health care, specializing in pediatrics, women’s health, and surgical services, to the Colorado area. The 422-bed acute care hospital is part of a large health joint venture system. The center operates a Breast Center and Diabetes Center, as well as centers for aesthetic medicine, female pelvic medicine, sleep disorders, and women’s health.

An acute care hospital, SMC has been a proud member of the community since 1945. Sage cares for more than 160,000 patients annually with a team of 1,300 dedicated non-physician employees, 100 volunteers, and more than 1,200 physicians. The emergency department sees an average of 100 patients per day. On its website for Emergency Room Care, SMC states that it has short wait times and patients will be greeted by a doctor in less than 15 minutes. And their “door-to-balloon times” for heart attacks averages less than 60 minutes, beating the national goal time by 30 minutes.

Patients in the ED have immediate access to the Sage Heart Center, vital for patients experiencing chest pain. The ED has board-certified doctors, specially-trained burses and other skilled and experienced staff. SMC specialized in dedicated pediatric care,
including board-certified pediatricians and pediatric specialty nurses who provide care in a child-friendly setting for 14 hours a day.

SMC was founded with origins in Jewish teachings, traditions, and community, with the goal to “serve the need of every creed.” By offering a high level of expertise and service across all disciplines, Sage has become a “destination hospital,” attracting patients from throughout Colorado and around the world.

SMC was named one of the nation’s 100 Top Hospitals in March, 2010, by a leading provider of information and solutions to improve the cost and quality of healthcare. This award recognizes hospitals that have achieved excellence in clinical outcomes, patient safety, financial performance, and efficiency. This is the fifth time that SMC has been recognized with this honor, and the second year in a row that SMC is the only hospital in Colorado to be awarded this distinction (personal communication, media contact, 2009).

Hospice of Saints

Like the religious origins at SMC, Hospice of Saints (HOS) was also founded on religious origins. The Sovereign Order of Saint John of Jerusalem opened the first hospice in 1048, as a medieval way-station for travelers journeying to the Holy Land. Since that time, the Hospice concept has evolved into a program that provides a home and specialized care for those who are terminally ill. The Sovereign Order of Saint John of Jerusalem has continued to flourish, adding new members yearly to carry on the tradition of providing care to the sick and dying. Plaques on the wall and quotes on the back of every business card at HOS communicate this tradition of care today that originated in 1048.
The Hospice of Saints was founded in Colorado by Father Paul von Lobkowitz, O.S.J. a priest, a nurse and an educator in 1977 and is the second oldest hospice in the United States. The hospice is accredited by the Joint Commission on Accreditation of Healthcare Organizations and is currently the third largest hospice in the state of Colorado. Since the beginning, HOS has provided comfort care to over 30,000 terminally ill patients and their families. HOS accepts patients despite their ability to pay, often providing care to patients other hospice programs have turned away. Countless times after charting patient information for the hospitality cart, I realized how many patients have no address and no names under family members. Even more, I have seen several patients with HIV, or patients who have no money, thereby reflecting HOS’s effort to fill the needs of patients who would otherwise receive inadequate care. According to the mission of HOS, its goal is to offer all patients the maximum quality of life possible throughout their final days, weeks, and months.

Hospice care seeks to alleviate physical, emotional, and spiritual pain by controlling the accompanying symptoms. The phrase “nothing more can be done for this patient” is simply not true for HOS. While it may be useless to continue curative treatments or surgery, hospice can still give attention, friendship, care, and love. The HOS is a religious foundation, but a non-sectarian health care environment, like Sage. The Hospice recognizes the need for emotional and spiritual support for the patient and family, both as a unit of care and as part of the care giving service. Support of the family and/or friends continues after the death of a patient for as long as necessary.

The philosophy of HOS is to provide patients, families, and friends a supportive and loving care in tranquil surroundings and the ability to live fully and comfortably for
as long as possible. Like Sage Medical Center, the patient is then permitted to die naturally with dignity and comfort when the time comes. The mission of HOS is to provide alternative, supportive, and loving care for the terminally ill and their families with an emphasis on life and living. HOS provides a team approach to medical care, pain management, and emotional and spiritual support. They refer to themselves as “providers of care” or “servants of the sick.” Together, they constitute an interdisciplinary team that includes members from all disciplines: medical, nursing, social workers, pastoral, dietary, volunteer and activity, bereavement and complementary therapies. On several occasions, I saw the team working together, collaborating in planning and providing care and documenting all activities and updates in the patient’s care plan. At their care team meetings, they communicated to me that a team approach allows individualized care for patients and their families’ needs and wishes.

In order to be eligible for hospice and Medicare benefits, the patient’s doctor and the hospice medical director use their best clinical judgment to certify that the patient is terminally ill with life expectancy of six months or less, if the disease runs its normal course. Patients choose to receive hospice care rather than curative treatments. The patient will then enroll in a Medicare-approved hospice program. Medicare pays a per diem rate intended to cover all expenses related to the terminal illness. Prognosis includes performance status including ECOG predictors (Eastern Cooperative Oncology Group score, a patient’s functional status recorded at admission), multiple symptoms, biological markers (e.g., albumin) and answering the question, “Would I be surprised if this patient dies in the next 6 months?” (Lynn et al., 2000). The Medicare hospice benefit provides four levels of care: routine home care, continuous home care, respite care, and general
inpatient care. Per Diem is approximately $150 per day, even with costs of new drugs and treatments rising faster than hospice benefit reimbursement rates. Certified hospices must offer all services if the patient is not covered by Medicare and does not have the ability to pay.

Description of Site Activities

The relationship between talk, knowledge, and discourse at these sites and between different individuals is critical to construct a meaningful account of the norms, vocabularies, and strategies used to understand what it means to live and die in the 21st century. In order to paint this picture, I ventured through the one-way glass doors of both sites, hidden mostly from public view, to the workers, providers, families, and patients who bear witness to the pain and suffering of death as well as the joy and hope of life. Specifically, I followed medical professionals at SMC through patient intake interviews, diagnostic consultations, bed rounds, interdisciplinary team meetings for twenty months, being there two or three times per week for two to four hours. Further, I observed and interacted with both patients and staff at HOS, to gather a wide range of viewpoints, including interrelationships between staff and patients, the staff’s perception of the experience, and the patients’ perception of that same experience. At HOS, I stopped volunteering 14 months after the completion of my research where I had been pushing the hospitality cart once a week every Friday afternoon for three hours into every patient’s room. I stopped volunteering in part because of my tight schedule as well as become uncomfortable with the difficulty of this project. Audio-recordings and observations of these site activities were conducted after consent was given by all participants to capture the dynamics of talk, knowledge and discourse in medical interaction.
Methods of Data Collection

As an ethnographer, I developed data collection with a general plan but have been sensitive to ongoing opportunities and restraints within the field, like feeling too comfortable or too trapped at both sites and wanting to talk to more people but not having the time and energy to do so. I have gathered data over a 22-month period, logging close to a total of 200 research hours and yielding more than 1,000 single-spaced typed and hand written pages of raw data including fieldnotes, analyses of training documents, and transcribed formal interviews.

Participant-Observer

Studying people in their own time and space enabled me to not only observe what individuals do, but how they understand and experience what they do. Participating in participants’ lives gave me a careful examination of the situation in which knowledge is produced (Burawoy, 1979). I still remain in contact with both sites. I have 850 single-spaced typewritten pages of raw data consisting of fieldnotes, interview transcripts, and other related documents (i.e., training manuals, documents, handouts, and meeting minutes). I also have handwritten notes, scratch notes, and audio-recorded field notes that I recorded when I couldn’t write and instead tape-recorded on my way home. I passed human subject approval for this research and all participants agreed to a consent form before participating and being interviewed. In total, I completed 15 in-depth interviews of clinic and professional participants including emergency department physicians, palliative care physicians, ED nurses, hospice nurses, nurse practitioners, medical residents, palliative care nurses, and case managers. Additionally, I completed a number
of informal conversations about these issues during my observations. Together, this empirical data has provided significant substance for the project.

More specifically, I began observing the ED upon invitation from Dr. Ryan who invited me to see medical workers “in action” in hopes it would spark some ideas for me and my long-standing interests in medicine, communication, and clinical life. I emailed Dr. Ryan after that observation, describing my initial reactions about life and death in the ED and I asked her if I could continue observing. She said, “of course.” After IRB approval, I observed the ED regularly with almost unlimited access, “floating” when not shadowing someone. I checked in and out with Dr. Ryan and shadowed her for two to four hours three days a week as well as other physicians, nurses, residents, interns, case managers, and triage. The ED is open 24 hours, 7 days a week, although my hours spanned between 9am and 12pm since the physician I worked with was scheduled 9am – 5pm or 4pm – midnight. Who I shadowed depended on when I was there, the schedule of others, the daily flow of patients, and suggestions from Dr. Ryan and other nurses. Observations in the ED also consisted of attending monthly ethic committee meetings in which I am now a community member, and morning bed rounds in the ICU. My role in the emergency department was primarily a researcher, while my role at hospice was a volunteer.

I started observing at hospice through the help of a palliative care physician, Dr. Jones who I had observed at the Denver Peak Hospital in the palliative care unit. Given my interest in discourse around end of life, Dr. Jones was instrumental in her discussions, knowledge, ideas, and recommendations to observe hospice. Dr. Jones introduced me to the nurse practitioner, Gerry, at HOS who was also instrumental and agreed to let me
shadow three days, four hours per day as she interacted with patients. From there, I went through 15 hours of classroom volunteer training, six hours of floor training and three hours of written tutorials online in order to be a volunteer at HOS where I pushed the hospitality cart and interacted with patients and staff.

For this activity, I entered all 40 rooms offering the patient and their visitors something to drink or eat or adjusting pillows, legs, lights, shades, fans in order to remain comfortable. This activity required no one else; just the cart, the patient, and me. Volunteer activities at HOS range from playing cards with patients, talking with patients, in-home visits, art classes, aromatherapy, massage, music and pet therapy, and hospitality cart. A volunteer who had been at HOS for five years left the time I had finished floor training so I transitioned into her role and have continued as volunteer, researcher, and friend on Friday afternoons.

Audio Recorded In-depth Interviews

All interviews were designed to provide additional background knowledge, assumptions, and expectations about patients and providers’ experiences and understandings around end of life. Interviews were also occasions for presentations of self and reflected the discursive construction of the individual talking. As Denzin (1991) claims,

The subject is more that can be contained in a text and a text is only a reproduction of what the subject has told us. What the subject tells us is itself something that has been shaped by prior cultural understandings. Most important, language, which is our window into the subject’s world (and our world) plays tricks. It displaces the very thing it is supposed to represent so that what is always
given is a trace of other things not the thing – the lived experience – itself. (p. 68)

I designed interview questions to elicit answers that elaborate upon inconsistencies and contradictions documented in observations, fieldnotes, and informal interactions. The questions elicit the way providers understand their role at the clinic as well as how they manage providing care around life and death. Their language and silence serves as a fragmented window into their world, their cultural understandings, and their experiences with life and death.

While the interview guide questions remained consistent throughout interviews, many questions were developed on an ad hoc basis or altered depending on the specifics of the ongoing exchange (Mishler, 1986). For example, my interview with a palliative care nurse happened before her shift so several questions were cut, and others added because of time constraints. My interview with a nurse from the ED took a different turn after we both started crying because of a story she had told me about a baby dying. I asked her if she wanted me to turn the recorder off and she said no. My interview with the chaplain from hospice had several interruptions with phone calls and other distractions; each time the conversation picked up someplace new. Furthermore, a question about what his job meant to him, made him cry as he reminisced about the first time he saw his daughter being born. Not knowing whether to stop or continue are the kind of specifics that guide or change direction in the interview.

Interviews were transcribed and all empirical material was analyzed according to critical discourse analysis. According to Deetz and McClellan (2008), “this research design engages the nested and interconnected nature of discursive moments, resources
and procedures, vocabularies, strategies, and techniques that are used by institutions and individuals to construct and sustain a coherent, stable representation of ‘organisation’” (p. 228). Using a combination of methods and working across sites, texts, and discourses, critical discourse analysis helps capture the ways in which discursive formations, value systems, and knowledge can become infused in organizing practices in process (Deetz & McClellan, 2008; Mokros & Deetz, 1996).

This combination of research methods and empirical material such as fieldnotes, interview transcripts and clinical documents analyzed together in order to let discursive practices, themes, resources and moments emerge in tension or harmony. These moments and insights into clinical practice create the spaces for hidden, partial, multiple and fragmented voices, and discursive resources to be uncovered in situ. The practice of critical discourse analysis allows a closer examination on the processes that distort communication in order to uncover alternative choices, values, and meanings suppressed in everyday clinical talk. Exploring these practices helps create conversations where none seem to exist and new ways of building more positive ways of talking, interacting, and making decisions around end of life. Therefore, in order to understand my second layered questions, I have drawn insight from a critical discourse approach to help answer these questions.

Critical discourse analysis provides the optimal means to study the micro-practices that organize meaning and experience around life and death. It is a practice that allows me to understand structures of medical talk, critique the varied meanings generated within clinical life, and attempt to find ways of understanding organizational realities and inherent conflicts within clinical settings that “directly connect the lives of
real people to real organizational situations” (Deetz & McClellan, 2008, p. 230). As a result, the analysis focuses heavily on the processes that distort communication in order to uncover alternative choices, language, values, and meanings suppressed in everyday clinical talk.

Focusing on the ways communication becomes distorted is difficult around end of life issues because not only do I need to understand what is happening, but now I am trying to critique what is happening. The ability to separate between insight and understanding, or the way the world works as others experience it from critique, what I take of their experiences is risky. It is risky for me because I have grown so close with these sites in order to understand issues as sensitive and meaningful as life and death to now trying to critique what is taking place in the ED and the hospice. As a result and remaining true to what others were saying, what I was hearing and what I was feeling made me feel crazy and incoherent at times. But these times are also the moments in which I understood the sites and myself differently. These moments also required the strongest of ethical commitments that I discussed with others to navigate the tremendous ethical issues embedded in the ED and the hospice.

Ethics in Research

The trouble, however, was finding commitments that matched the situations I was in and that matched the complexity of both sites. As a result, this study is guided by postcolonial ethics outlined by Gonzalez (2003). Note, however, that I am not claiming that I am a postcolonial researcher. Rather, I am claiming that these sets of ethics are the best I have seen to help me handle the situation I am in with these sites. In addition, I am
claiming that these sites are both colonizing sites. First, let me give you a small background on what I know about postcolonialism and why it is important for this study.

A postcolonial stance attempts to discover the essence to the story being told, or the “story behind the story,” which I have been interested in doing. I said these sites are capable of colonizing meanings, language, and even experiences about life and death so getting behind the colonizing story exposes how decisions, dilemmas, and choices unfold (Broadfoot, 2003). In doing so, it helps me see and create untold, unheard, unseen, and unimagined possibilities (Clair, 1998). For me, these possibilities have been hidden in my own complexities, subtleties, ironies, and contradictions of the way I experiences life inside the ED and hospice.

A post-colonial stance is not merely an act of defiance, but one of great courage (Gonzalez, 2000) if researchers inquire about the ethics of telling a personal story. The ethics of a post-colonial ethnography must be able to provide a means for telling a story that is accountable, and a story without “boundaries with culturally bound language, and allow its creative force to reach into the minds of others to create shared or competing realities” (Gonzalez, 2000, p. 81 as cited in Clair, 2003 p. 81).

My own assumptions, contradictions, and choices of this study have been documented in field notes and scratch notes to provide space and direction throughout the research process in order to be accountable to the people who shared so much, challenged me until the end to think differently, and ultimately opened up during a time of great vulnerability in the face of life and death. Accountability is the first ethic outlined by Gonzalez (2003). It demands a sense of letting go to have the ability to account or to tell
a story. But in order to know a story, it has to become part of the researcher. Therefore, the second ethic of context matters for how we tell the story behind the story.

Context is guided by my willingness and ability to describe the environment as the story unfolds and is told (Gonzalez, 2003). It is also the “ability to describe the political, economic, social and emotional environment in which the story is located” (Broadfoot, 2003, p. 72). Context is also the ability to know what is happening in the lives of the people about whom the story is told. Therefore, my own reactions and responses to interactions documented in field notes will accompany in-depth quotations in order to understand the sensitivity to language, the voices heard and the stories told. Although data collection spanned 23 months, I continue working with and am in contact with both sites as a way to underscore the role of truthfulness and relationship during my ethnographic journey.

Truthfulness, the third ethic, is also a practice of letting go of my own purposes and issues in life to establish a sense of reflexivity and reciprocity with the site, the people, and the stories. Truthfulness is about letting go of my own motivations, assumptions, fears, and confessions in field notes, during interviews or during interactions. Working truthfully solicits an open mind, heart, and soul. Anything less would be a disservice to those who have laid themselves bare in front of me often near the end of their life. Remaining truthful in the face of life and death places the researcher in a co-participant position so as to never forget how I choose to tell the story.

Community, according to Gonzalez (2003), encourages ethnographers to reflect on the consequences of sharing accounts and writing the story. Community reminds us that we can never be separated from those with whom we have and will share the story.
Throughout the research process, I solicited feedback, suggestions, and ideas from participants about the research design, interview questions, setting for interviews, and clarifying medical questions. My goal is for participants to provide feedback about the writing process, their stories and voices in order to enhance my own thinking and observations. In so doing, my hope is for the participants to be co-constructors of the research design and the writing of the research, which of course can be challenging.

These ethics are not easy to follow within an emergency department and hospice, nor are they easy to document in fieldnotes, as the sites constantly cut to the core of who I am and the meaning of this project for those who have co-created it. And at times, I couldn’t follow them. Therefore, despite its ethical commitments, this study will be partial and fragmented due to the people involved, the context in which it is embedded and the limitations of myself and other human beings. Being accountable, sensitive to context, and truthful while considering community is uncomfortable at best. But often, as Gonzalez (2003) underscores, compassionate sharing of a story can make others uncomfortable, not because we have chosen to be harsh, but because they are unaccustomed to our experience of reality. And practicing these ethics throughout the research process has shed light on where my body and mind are colonially trapped.

Throughout this project, I have experienced my own set of health issues starting in my heart, resting in my stomach, my blood, and ending in my digestive tract. Aside from the number of doctor visits, lab work, and uncertainty, one thing was clear: I have affected this project, and this project has affected me. Despite feeling angry and disappointed, I have been humbled for the better and the worse by the courage and commitment called forth as human beings, patients, providers, and researchers in this
frail and fragile existence. And without writing and reflecting through a high degree of reciprocity, I would be lost.

Reflexivity and reciprocity underscore the challenge of speaking for others when we write, present our data, and tell stories, which is interrelated with the politics of representation and the crisis of legitimation for research in general. But speaking for others requires an uncanny sense of irony. For me, it is less about speaking for someone and more about saying what I heard. Just listening to others is not enough and isn’t fair since we are always already positioning what we hear, how we hear it, when we hear it, and what we say about what we hear. Therefore, in this study, I respect the irony of representing the voices and stories of others in order to re-engage what I thought I heard in order to make it meaningful and accessible to the people who have shared and helped create this story. But as in any heartfelt story, I have contaminated this study with my lived experience. And my study has contaminated my understanding of myself as both a researcher and a mortal being. Therefore, engaging in models of reflexivity through creative and alternative forms of writing, as I have done here, is necessary to contaminate the body of social science knowledge with the messiness of lived experience. Even more, by reclaiming contamination as an organic process of knowledge production grounded in human experience, I hopefully resist seeking to clean up the mess of lived experience rather than reveal in it (Ellingson, 1998). What follows is an example of how I reveal in the messiness of this clinic in light of my ethical commitments.

My reflective experience: The clock in the ED read, 22:01. I was standing at "my post," a wall next to the triage receptionist desk that faces Bed one. I had left for the restroom and during those 7 minutes, the bed had been filled. Bed one is for most acute
patients and they are structured hierarchically along the rest of the hallway. I look into the
dimly lit room where a man is lying whose stomach is protruding outwards. He has light
gray hair, most of which is fuzz. And two women are standing on opposite sides of the
stretcher as Doc comes around from the corner.

"Sad situation, I'll fill you in, come sit down," she says.
She pushes out a rolling swivel chair while looking at a recent chart of the patient in bed
one. She mentioned some medical jargon and numbers, most of which were foreign to
me. She interrupts herself and says,"enough of this, let's go see him."
I sigh and follow behind. Doc introduces herself and me and asks the woman if I could
stay. They both smile and nod in agreement. I lean against the sink and the younger
woman, who’s about my age, remains standing on the side of the stretcher. Her right hand
is holding her dad's hand and her left is stroking his head. The older woman, the mother,
who looks about the same age as my mom, has taken a seat next to Doc on the left side of
the stretcher. Doc asks how they are doing.

"Dad, you still with us?" The daughter asks loudly.

"Dad, you with us?" She says again and her father rolls to the right and smiles
every so slightly.

"Thank god, you scared me," she says.
Doc asks a few more questions and the mother bursts into tears. The daughter breaks
away from her father’s hand to walk over and give her mom and hug and a kiss on the
cheek and then back to gripping her father's hand.

"I'm so sorry" the mother repeats.
I was about to lose it and burst into tears. Why did I feel so close to this family? Doc
says we'll let you have some time alone and be back in to check in a little bit. The mother nods in agreement.

"Dad, you with us?" the daughter asks.

"Dad! Dad! You with us? Come on, Dad, please stay with us! The daughter yells as we start walking out.

I looked at them both as I made a turn toward the door and smiled with my lips pushed together and inwards. But my cold smile felt so weird, artificial, and so wrong. Who was I right now? A daughter? A sister? A friend? A researcher? How would it change the way I was standing, the way I was breathing, and what I said if I have enacted one of my other roles? I walked out as a researcher, but it felt so disembodied, so shallow to do at this moment. What did I want to do? I wanted to start sobbing and give them both a huge hug and tell them how sorry I was they had to go through this.

Doc sits back at the computer, I grab my bag and tell her I am taking off.

"Really? Everything okay?" She asks.

"Yeah, thanks. See you Sunday," I reply.

I walk out the glass doors and not realizing what I had done until exiting off the Interstate on my way home: I had left. More importantly, I could leave. Doc had to help and be with patients for another two hours after her already six-plus hour shift. She couldn't leave or "get some fresh air." The family in bed one couldn’t leave either. But if they did, they would leave with the illness. I did not.

Reflexivity in Fieldwork

Moving between patient, daughter, sister, friend, and researcher, my understanding of clinical experience has endlessly been contaminated by this
uncomfortable shift in perspective or role. Therefore, my own lived experiences with death and dying thoroughly contaminate my analysis that result in a rich, complex understanding of the providers and patients of the clinics I observed (Ellingson, 1998).

My understanding of patients’ experiences is shaped in two ways. First, I have a basic technical understanding of the diagnostic tests and treatments. Second, I share with the patients and providers an interest and commitment to productive communication and care at the end of life. Together, I believe they provided the basis for increased trust and openness in our interactions. This matters because I believe researchers must achieve partial identification with the people one is engaged in studying (Mies, 1983).

Partial identification is a form of reflexivity that involves being simultaneously close to and distinct from what or whom I am studying (Ellingson, 1998). Through the blurring of boundaries between researcher and researched, the interplay between these becomes a focus of interest. For me, the interplay of these relations is where the interesting stuff happens. It is not in the distanced reading about these sites that my understanding of these patients and providers has been born. Rather, it is in the gut-wrenching, tearing inducing empathy with the pain of illness and the loneliness of disease and dying that I felt I understood these people and myself. But empathy is a complex responsibility for people who are terminally ill. When I am identifying with both staff and patients, I am experiencing the effects of my academic training as a communication scholar constantly shifting perspective frequently, within a matter of minutes or seconds, just as the providers, families and patients do as well. As a result, explicitly reflecting about the limitations of my own thinking and speaking, and the ways I distinguish what
end of life is so I don’t reproduce the very practices I am critiquing, matters for effective
models of reflexivity (Foster, 2008).

Reflecting on the limitations of my thinking and speaking serves as a reminder
that discovery is not so much uncovering an objective external reality in a clinical sense,
but the growing awareness of our intimate involvement with our subject (De la Garza,
2004). In other words, we are part of what we observe; we shape it just as it shapes us.
Reflexivity in fieldwork is uncomfortable, full of passion, contradiction, and
vulnerability. It is a process of trying to let go of all I think I know, even as my own
experience and the experience of others creates enormous barriers for letting go.

This research report is written largely in a realist style, as well as through creative
and alterative forms. My hope is to become part of the interaction and provide an
interesting, evocative, compelling, well-written research report that might arouse and
question seemingly “normal,” “non-messy” accounts of clinical life. The narratives break
into this project in much the same way that they break into my heart and train of thought
as I write. Many scholars (Behar, 1996; Denzin, 1997; Ellingson, 1998; Ellingson &
Buzanell, 1999) argue that in order to enhance understanding of communication theory
in medical settings, the only research worth doing is painful and messy. But what many
don’t argue or explain is what happens when researchers reach that point of complete
immersion, letting go, or that point in the project that literally breaks your heart. Further,
what many don’t say is how terribly difficult and uncomfortable it is to write when your
heart hurts. My heart hurt when I left both sites. Both challenged me to continue talking
or even writing about the project for a while. I had met with my advisor and talked with a
committee member over the phone describing the crisis I was having. After inquiring if I
was okay, they both encouraged me to write in a document different from my
dissertation. So I wrote and wrote and wrote. When my heart wrenched feelings poured
onto the page, I was ready to come back to my project. The next chapter exposes these
very un-candid and un-edited reflections of what took place when I left these sites that
had once been my comfort zones.
Chapter 6:
A Crisis of Reflexivity

I’m breaking down, literally. The past few months have been spent getting even closer with my data while still remaining in the field on Friday afternoons. I’ve primarily been reading through fieldnotes and re-reading interview transcriptions. Writing notes from the ED came naturally: I saw, listened, and reported. But I am not sure if I ever really let myself feel what was happening when I was there. At the beginning, the smell of the ED made me want to vomit. And the artificial florescent lights burned into my head without even knowing it. I put lavender under my nose and on my wrists every time I entered the ED for the first few months and drove with the windows down, despite the weather, across Hospital Blvd to Ellsworth until I was on the highway.

The disinfectant that scoured the floors tingled my nose and shot through my head. The excessive Purell squirted on every one’s hands, foaming in and out after each patient became a saving grace as I found myself squirting it too so I could inhale the rubbing alcohol smell by bringing my hands to my nose to cut out the other odors. Interestingly, I became immune to this smell and the irritable sound of beeps and bells that orchestrate every second in the ED. Even more, I grew impervious to most patients, and most conversations when I was there. In a sense, I had developed my own form of armor for being present. Yes, I ran out on occasion or burst in to tears when I left the ED and was alone in my car. I thought every hour I was there how fortunate I, or someone I knew, were not in bed one, bed two, bed three or bed four.

Reading my notes a year later, I am taken aback that I was there and saw the things and heard the things I reported. And so too, that everyone around me saw and
heard the same things but through different eyes, of course. In the ED, patient ailments range from a stubbed toe, to a fractured foot, cuts, bruises, chronic headaches, liver disease, kidney disease, HIV, and terminal cancer. But patients never stayed long when I was there. Patients were either admitted into the hospital, went home, or died. In any case, the ED rarely saw them again.

The patients I saw die, died quickly. For example, one patient came in with hardly any pulse and freezing. He couldn’t say anything and therefore his POA spoke for him. The resident on duty knew that time was precious and continued to find out what his wishes were if his heart were to stop. The resident said, “should we do everything possible? Or should we let him die without ‘trying’ to save him?” “Let’s try once more,” his POA said. And that is what the doctors and nurses did when his heart stopped. The patient died the next morning.

Another time I had arrived to the ED and stood in my usual spot, the unruly mess of bed one literally created its own mess in my stomach. Monitors were on the ground, sheets that looked like they had been ripped off were laying half on the bed and half on the floor, wrappers from IVs were covering the tile around the bed and cords were draped over and under the bed.

“What happened in bed one?” I asked.

“Patient coded and didn’t survive,” the tech said quietly to me.

For many in the ED, a messy room is symbolic of a “fair death,” meaning the team did everything they could. Essentially, the messier the room, the harder they worked to save a life. These situations happened too often and too quickly for me to understand
in the moment. But one thing was clear: I was ready to see how death was understood and dealt with in another place.

In between transitioning sites, I contacted Dr. Jones, a palliative care physician, to get her opinion on where I needed to be to get a better understanding of death and life in medical settings. She invited me to observe a daylong palliative care rounds while she organized a visit to hospice, which was her recommendation for where I should go next. I observed palliative care rounds at Denver Peak Hospital and was mystified by the harmony that occurred when a team consisting of one doctor and two nurses went bed to bed, spending a minimum of 45 minutes with each patient. The care seemed honest as they turned away blood samples and MRIs as a way to bring comfort to a patient who was dying. They knew so much about each patient. For example, they knew that when Laura was crocheting, it meant she was feeling well. Laura, tan skin with short wavy dark hair, didn’t have her needle and yarn out the day I visited, which meant she was in a lot of pain. She cried when the team was there and begged them not to leave if she fell asleep. Her belly was swollen and her face puffy as her eyes dragged between opening and closing. Dr. Jones held her right hand, staring into her eyes. Helen, one of the other nurses held her left hand, also staring into her eyes. Joan, the other nurse had her hands placed on Laura’s ankles gently massaging them.

This level of care astonished me. Feeling refreshed after seeing it, I felt ready to see what goes on at hospice and why several doctors and nurses thought I needed to spend time there if I was ever going to understand death and dying. Dr. Jones gave me directions to Lakewood but I had some trouble finding it. I called the receptionist three times.
“Turn on Ellis Lane,” she kept saying.

Below Ellis Lane, is the sign, “no outlet.” Driving down Ellis seemed a little dodgy from the start. Two tired looking apartment complexes with covered windows, people smoking on the stoops, and balconies with signs advertising “reduced rent,” lined both sides of the street before seeing the hospice, which is at the “end” of the street. The chapel was first on the left, then two cream colored buildings or wings with several windows on the perimeter. The American flag waves above the parking lot. Bird feeders line each room’s window, some stocked with seeds and some not. The buildings have on story. And there is a smoking lounge at the east entrance. Gas-lit fireplaces sit in both lobbies.

I met Gerry, the nurse practitioner at hospice Wednesday morning at 8am. Dr. Jones had suggested I spend three full days to get a feel for things. Before sitting down, Gerry grabbed a cup of Chai tea from the machine and I hesitantly poured myself a coffee from the machine. Struggling to sip my horrible coffee while smelling her Chai, we talked about my motivations for coming, as well as her role at the hospice. We sat in the west side kitchen on a wooden table with a plastic cloth and carination as the centerpiece. I immediately like Gerry. She invited me to put my bag and lunch in her office before we started the day checking in with patients. Gerry moved slowly and so did every one at hospice.

The lights were much dimmer at hospice than in the ED but the smell that I became impervious to was back. The carpet is a dark gray and the halls entrapped me. The scary stillness of death was new for me. The ED felt like a happy playground compared to here. Gerry’s office was in the nurse’s station, filled with artificial light. It
was closed off by big glass windows – the standard kind of window often at doctors’ offices that slide open when someone approaches and slide closed when they leave. We had lunch together that day and again another day with Dr. Jones who rode her bike to work. They asked me how things were going but I didn’t have much to share except that the hospice was new to me and I never imagined it would be so different from the ED.

Two days went by with Gerry, but I couldn’t return until day three. I felt terribly sick and remember driving home wondering if I should pull over and vomit or whether I could make it home. I emailed Gerry that night, telling her that I wouldn’t be there in the morning because I wasn’t feeling well. She wrote me an email and called telling me how much she appreciated me not pushing myself to return and that every one of us handles being there differently, so it’s important to listen to your body. I did listen to my body and didn’t go back for a month. Then I decided to interview Gerry after that to talk about her experiences, training and so on. We met at 8am again and sat in the kitchen on the east side, next to the fish tank with the loud filter. A small family sat a few tables away for an admissions interview and the kitchen staff was busy preparing the next meal. Gerry and I talked for over 30 minutes and it helped me to hear about the purpose of hospice. She encouraged me to volunteer there, as long I felt okay. She emphasized several times how the hospice is such a special place.

I talked with the volunteer coordinator and my interview was the week of my comprehensive exams. My new-hire orientation was three weeks. The training lasted two days from 8 to 5pm, lunch included. We covered several topics and heard directors describe the history of The Hospice of Saints; hospice and palliative care philosophies and concepts; complementary therapies; infection control; safety; pastoral services; social
services; cultural care; dietary-comfort kitchen; death and dying; bereavement; communication; and pain management. Slowly, I began to share a similar vision of hospice shared by many who walked the halls, that this was a really wonderful place. A week later, I started my six hours of floor training pushing the hospitality cart. Two weeks after that, I started my new job every Friday afternoon from 3-5pm. I went in to every room were patients weren’t being bathed, or sleeping, “on watch” or had visitors. Many of the patients seemed to enjoy talking to me wondered why someone so young would volunteer there. After each shift, in official binders, we had to document what they had to drink, what they had to eat and anything interesting or unusual about their mood. This took me almost an hour every time I was there.

At the end of each log is the patient’s information: date of birth, religious views, primary physician, address, admitted from, family names, and diagnosis. And sometimes there was a small paragraph describing their childhood. Many of their histories were sad for me, without an address and without family members or a power of attorney (POA). Many were from foster families, many had their own young kids and many were young themselves – 20 and 29 – and as old and 98. Every Friday brought new patients, meaning some had died or gone home, wherever and whatever that meant for them. Every Friday, before I knocked to enter each room, everything at the hospice began to wear on me. What was wearing, I’m not sure, but I was overwhelmed with the patients’ unending pain and suffering.

The nurses I interviewed and the training I went through reiterated the naturalness of death and in many cases, the beauty of a “good and peaceful” death. Did these patients know that when they came to hospice, at least someone was certain they were going to
die, and die pretty soon for that matter? What is it like to hear that from someone? What does it feel like to come to hospice as a patient? I continued opening ginger ale cans and bags of Doritos for patients. I was walking a fine line between opening the can, or bag of chips, and letting them do it themselves knowing their mobility skills were declining yet also aware that opening a can, a straw, a bag of chips was one of the only things they could control.

I started having bizarre dreams at night. They weren’t about dying or hospice or medicine, but just busy dreams full of activity. I went back the following week to hospice, seeing patients differently while hearing in the back of my mind, that death is a peaceful and beautiful thing and at hospice, they see God working. At hospice they embrace life. Really? Is this what life looks like when you’re near the end?

What is beautiful about dying? What is beautiful about sitting in bed, looking at the TV or out the window for five days, three weeks or eight months? What is beautiful about experiencing enormous loss – a loss of privacy, a loss of support, a loss of mobility, a loss of appetite, a loss of communication skills, a loss of memory, a loss of feeling the ground, the wind, the rain, the snow, and the sun?

What is beautiful about a slow death? What is beautiful about an immediate death? What is beautiful about eating salty and processed food and having to eat when someone serves you? What is beautiful about not being able to brush your teeth, comb your hair, remember your children’s phone numbers, or remember how to even use the phone? What is beautiful about feeling like “a cattle at an auction” wondering where you will go next and if someone will accept you? What is so beautiful about wondering if your weight gain will continue to be supported by Medicare because essentially that
meant you were getting better? What is beautiful about losing most, if not all, of your possessions? What is beautiful about not having a “home” to go to? What is beautiful about wondering if you are in fact, dying? What is beautiful about seeing or hearing people squirt hand sanitizer on their palms before and after seeing you?

Last time I was at the hospice, a patient had contracted C-Diff. Outside his room was a cart filled with yellow gowns, yellow masks, and rubber gloves, are required to enter the room. I was pushing the cart that day and wheeled by once or twice to peek in, wondering if I should “gown up” or not. Three visitors were in the room wearing the masks, gowns, and gloves on surrounding the patient’s bed. I wheeled by a third time, stopped the cart outside, caught their eye and while pointing at the cart said, “care for anything?”

“No, thank you” the woman responded.

Did she know I was too scared to enter? Why didn’t I go in? Well honestly, because I didn’t want to catch the bacteria. Was this a selfish move on my part? Was it fair? How many others were taking the same approach I did? Dying here is already so lonely, not to mention when you have to wear protection to be in their presence.

What is beautiful about dying alone? What is beautiful about dying here? What precisely is beautiful about dying anywhere? Even more, what is so rewarding about working in these places? How could this work feel good to people? How are they able to sleep at night, seeing six people die in one day at hospice or seeing a full code in the ED? The jobs feel dirty to me, yet they almost seem to make an otherwise dirty job clean. Why isn’t anyone experiencing the horror, the fear, and the depression that I am?
In a sense, we can die at home, in transit, in the hospital or in hospice. At the ED, it now feels as though death was more real, more honest, and less painful. It happened quickly, from what I saw. Life and death are fleeting in the ED; it comes and goes fast. At hospice, it feels like life has already gone and there is only death. Is the approach and purpose of death at both of these places similar to their approach to life? Who is deciding what a good death is, and what a good life is? How can someone actually be trained to see the beauty of death and even believe that death is something natural and shouldn’t be feared? How did I spend so much time in these places?

I don’t want to die in either one of these places, nor do I want any of my family or friends to either. In fact, I wish no one would have to die this way: long, slow, and lonely. Is it that only the unlucky ones have to die this way?

What is divine about work at hospice? What is the role of faith in creating a peaceful death? What is the role of worship and religion in creating a peaceful death? Can you die peacefully without believing in someone or something larger than the self? Can you work at hospice and the ED without believing in something larger than the self? How can workers stomach the pain, the morbidity of these places? I cannot anymore.

Empathy is one of the key characteristics of both places. To me, empathetic people feel much for the Other. By capitalizing the O I draw attention to a set of situations or moments that fundamentally challenge who I am and what I hold to be true. The presence of Otherness is also the presence of difference. Further, it is an act of destruction of meaning that through its encounter, something challenged me so much at these places that will never allow me to come back to the way I was. In short, Otherness,
is the very moment I began to see death in a way I was not able to before. Consequently, people suffer when the Other suffers.

How do they deal with their suffering? Are they able to? How exactly are they so courageous to care for people who are ill and dying? How are they so courageous to shift mindsets between someone dying, ordering pizza and telling someone they have a terminal illness? Who is calling on them to go to these lengths to save and help others? Where do they find courage and compassion to care for some one else, including their own self? What does it feel like to control someone’s death? What does it feel like to be responsible for how, when, and if someone dies?

What happens to life when all of it disappears? Everything you ever felt, ever experienced, ever loved, ever saw, ever tasted, ever knew, ever read, ever heard, ever listened to slowly escapes you? What is left? What does it mean if the things I take to be so important in life lose meaning at the end? What will it be like if I forget these things when I get older? What will it be like if no one cares about these things when I get older? What is left? What will it be like to die without anyone I know surrounding me? This scares me tremendously. But how do you manage these fears? What is the meaning of life if it ends this way, stuck in an uncomfortable bed, eating salty and processed food and looking out the window at a birdfeeder? Why is life so sacred? Why is death so profane? And why are both so fragile?

Many know that the ED operates at lightening speed and their purpose is to fix em, get em’ out, or save em’ if they can. And most everyone knows that hospice is for people who are dying and don’t want “aggressive treatments.” For the ED, going to hospice means patients are stopping care. For hospice, coming there from a clinical
setting, translates to patients being cared for, for the first time in a while. People talk about “going on” hospice, or “coming off” hospice. What exactly are they going “on” or “off?” Is it similar to the tragic ride I went on and now slowly coming off? How do meanings that surround life and death change instantly, where focus is spent on managing symptoms and bringing comfort to patients in their last moments of life, opposed to doing everything possible to keep someone alive? How exactly does this work?

Since many patients are admitted from the hospital to hospice, how do patients and families process, “stopping clinical care?” They have a terminal illness but aren’t being treated, so to speak. There is no chemo, no radiation, no aggressive medications or treatment at hospice. But there is aromatherapy, pet therapy, music therapy, pastoral services, art services, pain medications, and volunteers that serve as their own form of medicine. If a patient doesn’t have a strong belief system, how do they process their experience at hospice? Likewise, how do workers process their care without a strong belief system? Does religion and spirituality prevent things from being said or from not ever being dealt with?

Religion and spirituality provides people with answers and in many cases can serve as a sense making device for a rather complex situation and morbid experience. Does religion and spirituality provide a sense of armor for those at hospice against death and dying? Do people really see angels before they die like that say they do? Do people really see “a light” before they die like they say they do? How do you move “bad” energy in a place with so much death? What do people in the ER believe in to help process their experiences? For many of them at the ED, talking about death and dying is not in the job description.
An ambulance arrived to the ED with a patient who had coded during the ride over, but he was admitted to bed 8. I walked behind doc and two nurses to meet them. The EMTs were transferring the older man from the stretcher to the bed while the family watched. The doc introduced herself and walked over to the patient whose mouth was slightly open, took her stethoscope, placed it to the older man’s chest, spread open the patient’s eyes, removed them, looked at his daughter and said,

“Yes, he has indeed passed. We’ll leave you alone in the room, but please let us know if we can get you anything. The nurse will be in to discuss where you’d like us to take him shortly” the doc said. We left the room and we were on to the next patient.

What kind of people can do this work, seriously? What about me can’t handle it right now, or ever? Are these sites different? Are they similar? Do they use similar logics? Do they use similar communicative strategies? Does the average person feel what I’m feeling when they go to these places?

It’s never been clear why I chose this project. The only thing I can think of is that this project chose me for some reason. I have no expectations other than to understand what happens in these two sites: what is death, what is life, what kind of care emerges, what is the role of the patient, the caregiver, the self, and what is the role of communication in maintaining the purposes of both places: to heal and comfort. What would a good death look like? Is that even possible to imagine? What would effective end of life care look like? And is that even possible?

At the beginning, I thought the ED would be more difficult for me to sustain as a researcher, a graduate student, and a 27 year-old daughter, granddaughter, and sister. I was disgusted at times with what I saw and what I heard. But I have also been astonished
with the care, courage, intelligence, compassion, and strength of patients, families and providers in the ED. Hospice was going to be a saving grace in the messiness of death. Or so I thought. It was going to be a place of comfort, people enjoying their last moments living without needles, cords, and machines. For some reason, those artificial noises are comforting in the ED. At hospice, the silence rattles my soul up and down. Patients’ bodies swollen, bandaged, wrinkled, white, green, bald, blind, deaf, cold, smelly, motionless, and crippled desperately haunt me. At hospice, I see how illness and age literally take over bodies, skin and minds every week. Are they just unlucky?

Am I unlucky? Or have I literally become undone, as Broadfoot (2005) talks about? Or have I been touched by the center of Geertz’s Balinese Cockfight as Deetz asked? What does it mean when you get to a place of complete engagement? What happens when going native is painfully uncomfortable? Is this where the interesting stuff really happens? What if you can’t stay once you get here? What if the human instrument is experiencing compassion fatigue as Tompkins calls it? What if the human instrument, in fact, is not able to see, hear and feel the world the way they did before they started this project? Where do you find the courage to go forward when you’ve hit rock bottom and feel as though there is nothing fair about living and dying the way many do? What is the meaning of a project that literally gets inside of you? What is the purpose of a project that makes you feel so empty, so lonely, and so sad? What are you able to think, understand, say, and write when you reach a place of discomfort with the sites you’ve been called to for the past two years?

I went back to hospice last week to push the cart a full year after starting. A false fire alarm congregated almost everyone but the patients in the main lobby. How would all
of the patients get outside if there was a fire? Would people have to make choices? Would patients be okay outside since many have not been exposed to actual sunlight in awhile? Too many questions ran through my head. I proceeded to prepare the cart and check the chart for any updates. The stringent smell of Clorox and urine ate through my stomach.

I started in room 101, where the patient ordered a coke. Room 102 had no request. Tom in 103 had no request either, but after I asked him if there was anything he nodded and said, “get your ass over here to hear that I don’t want anything.” I would have probably said the same thing if I was sitting there in that same bed and someone on foot offered me a soda or chips, or “anything else.” I looked across the hall into 104 leaving Tom’s room and saw an older man, balding, mouth frozen yet open slightly and a trach inserted in his throat with the machine working hard next to him. A nurse was filling water and I asked her if I should enter.

She shook her head, “No, I am pretty sure they just put him ‘on watch.’”

I waited as she walked to the nurses’ station, watching the patient breath by himself in the dark room.

“Yes,” she said. “He just went on watch.”

Alone I thought, again. On watch carries so much weight for me. Who is doing the watching?

“Gosh, that’s sad,” I said softly, not thinking any one would hear.

The nurse turned around and said, “Yeah, hopefully he’ll make it through Easter.”

I looked back at her and said, “I hope he gets to go sooner, he doesn’t look very good.”
“Yeah, I guess so,” she said. “I’m praying for the instant car accident, train wreck and so on kind of way out.”

I nodded my head and said, “yeah, me too.”

Room 105 had no request and Gretel had her usual glass of half wine and half water, although she thought it was all wine. She was folding napkins in the kitchen when I poured it for her wearing one of her many knit caps that she always wore.

“Anything else, Gretel?”

“No, my dear. But you know that I love you, right?” She said.

I nodded again and said, “I love you too.”

Room 107 and 112 were in the smoking lounge and wanted a beer—one had a Coors and the other a Bud light. Room 108 was also “on watch.” Room 109 never ordered anything because he has a horrible disease and feeding tube. But his wife is always there and takes a few diet sodas and Fritos or Cheetos. She is missing a bunch of teeth and always tells me how exhausted she is working mornings and evenings at her two jobs and coming here in the afternoons to be with her husband. I wonder sometimes if she takes extra things from the cart for her own meals at home.

Room 113a and 113b were empty. Harri was in room 114. She doesn’t have very good eyesight per the nurse’s note and through obvious previous interaction with her. She stares at one place no matter where I walk, so it’s important I start speaking at soon as I knock so she knows who is there. She is sitting on the edge of the bed watching Ellen on TV but didn’t want anything from the cart. The note on my chart said, “Ellen is becoming confused about why she is at hospice and if she is ‘dying.’ Please help her process by
actively listening and use open ended questions.” What question could I have possibly asked her? And what could I have said if she asked me if she were dying?

Across the hall in 115 the door was closed but the nurse walked out and said one of the visitors would love a diet 7up. I handed her one and wheeled the cart toward room 116 where a nurse was using a pen and pad of paper to communicate with the patient. I waited by the door and knocked quietly. The patient looked at me and then the nurse turned around and said, “oh no thank you.”

I walked out and a visitor was walking in. “Do you care for anything,” I said. She looked at me, shook her head no and kept walking. Room 117 was empty, and so was bed 118a and 118b. Next side.

Before I walked to the west side, I stopped at the main office to see if there was any mail to be taken over. And there was, including a box of flowers. I was planning to drop the flowers and five pieces of mail off for room 203 before starting but the door was closed when I got there and three adults with pen and paper were surrounding the patient’s bed. I peeked in and caught one woman’s eye that stared at me and subtly nodded no. I scurried away and left the flowers with the nurses to deliver and I put the mail on the cart. I started in 201, Joan's room, who almost always is sleeping with her mouth open and feet exposed in a pigeon-toe position. She has beautiful white hair and moist skin, and I have never heard her speak. Room 202 was empty. The visitors had left in 203 so I knocked, was welcomed, and handed Lee the mail. She was cutting her flowers and asked if she or any of them cared for something to drink.

“Want a gin and tonic, Lee?”
“Sure, I guess,” she said. “But in a plastic cup, pointing to the one on her stand, with a little gin and the rest tonic.”

“Anything else?” I asked.

“I’d love a glass of Cabernet,” one of the women said.

“Sure, I’ll be back soon.”

I went back to the closet to get the gin, tonic, and plastic cup. I walked back and placed Lee’s drink on the table and handed the wine to the visitor and walked out.

Charlotte was on the phone across the hall but not for long. She couldn’t get the phone on the receiver so I walked in, moved the blankets that were blocking her angle and she put the phone down.

“Hey Charlotte, how are ya?”

“Oh, so far so good,” she said, as what she always said.

“What’s new?” I said.

“Nothing really, except I am so tired of people always wanting to clean me. The nurse was in here two hours ago to clean and she just came in to say she needed to clean me again. And I told her, I am not dirty, I’m tired and I want to sleep! It’s like she has nothing else to do!”

“Did you tell her you don’t want to be cleaned?”

“Yes, several times but no one listens and you can’t do anything here, they are always cleaning me up.”

“Maybe she just really likes you, Charlotte?”

She laughed. “Yeah, maybe I need to start being mean to these people so they leave me alone and stop taking advantage of me!”
“Well, I am not going to take advantage of you but do you want a 7up or Ginger Ale from the cart?”

“Yeah, 7up sounds real good.”

I opened it, put it over ice and told her I am leaving so she can sleep. She smiled and shook her head in frustration to being cleaned, again.

Room 205 was on watch. Room 206 was visiting with another volunteer so I kept walking. Jay in 207 is diabetic and looking for pork skins and asked me to please have some one get them at the market while he enjoyed his diet Pepsi and Fritos I had brought him, which had sugar. Room 208 was empty. I had mail for room 209 who was sleeping, so I left it on her table next to one of those picture frames that slideshows endless photos from a memory card. Room 210, 212, 214, and 216 were empty. And room 218 was on watch, with no one around. Room 220 was also empty.

Violet in room 222 was awake for one of the first times. I gave her the mail and offered her a Ginger ale since her daughter has told us she likes them.

“Hi Violet, I have some mail.”

“Some milk, great, sit down.”

I stayed standing. “How are you?”

She laughed. “Let’s not have chicken tonight.”

“Ok,” I said, “no chicken.”

“Yeah, we’ve had it too much” and mumbled a few things after. “Are you coming to dinner?” she said.

“Well, no I can’t because I have to go home and eat there.”

“Ok, sit down, have some milk, maybe some cream” as she reached for the table.
“Can I get you something?” I said.

She laughed and said, “Sit down.”

I walked closer and said “okay, but would you like some ginger ale?”

“Some milk? Why don’t we have hot dogs for dinner and we’ll have” and mumbled some other things.

“I can’t stay for hot dogs but your dinner will be here soon.”

“Why can’t you stay?”

“I have to go home and eat with my brother.”

I didn’t know what to say but we’ve been trained at hospice to follow the conversation if this happens.

“Yeah, your daughter, I mean granddaughter is dating someone so you better go.”

I smiled and told her I’d see her soon. Her slipper had fallen off so I went to put it back on but she shook her head no so I took the other one off too and she smiled. I touched her foot to say goodbye and she looked startled and stared at where I touched her sock for a minute. I said bye again, she looked up, said bye and laughed.

Room 223 and 225 were sleeping so I wheeled the cart back to its place, walked across the black asphalt parking lot to chart each patient in the white binder. I left hospice at 4:45pm that Friday night and drove out on Ellis Lane with my window down. I headed west on the Intersate with one thing very clear: it is time for me to leave the field. The next two chapters will develop how providers’ at both places understand and experience these places, and interestingly, how differently they manage the chaotic nature of death compared to myself.
Chapter 7:

Dealing with the Complexity and Messiness of Death in the Hospice

The last chapter gave you a sense and hopefully a deep feeling for the world as I experienced it when I entered hospice and the ED. Some of it, I hope, helped you see and feel just how wild and chaotic death is, and can be. Even more, I hoped that the last chapter brought a new face to the courageousness of the workers, the healers doing this work. This chapter develops the world as the providers at hospice know and experience it. 

In both the ED and hospice, death is chaotic. This is an enduring tension for life and work at both locations. Through organizational routines and practices, providers, patients, and families are able to tame temporarily and therefore deal with the complexity and messiness of death as well as their own humanity. 

Aspects of this tension are experienced from the first moment people arrive at either the ED or the hospice through an un-stripping of humanity that takes place. This un-stripping will become more clear as workers describe their experience of caring for patients in their last moments of life. This un-stripping also comes from seeing patients at some of their most vulnerable moments where everything we believed to matter in life is suddenly taken from us. 

The tension is especially pressing at hospice. At hospice, staff workers see and experience this un-stripping while promoting, if not promising, that death is indeed different. This means living every moment to the fullest until you die. Seeing this un-stripping from any perspective can be horrifying, but even more when your role is to
some how say and promise that death is different in hospice. This chapter will focus on the hospice and the next one will focus on the ED.

In many ways, I experienced this tension when my idea of death slammed into my experience of death in the ED and the hospice. I did not know how to make it less chaotic or figure out how to make sense of this tension. But what I have discovered listening, observing, and talking to providers is that they, too, experience this tension. They also manage it in fascinatingly different ways. Specifically, in what follows are three ways that I believe providers handle this underlying tension between an un-stripping of humanity and the promotion of life and a good death at hospice. Specifically, embedded in each of these practices for managing this tension is a rehumanizing of their care practices.

Death is chaotic at hospice but a daily routine tames dying to allow what otherwise would be a disorderly place to become a place perceived to be orderly and coherent. Even more, in both places, the workers are also un-stripped. Both professions are helping and healing professions. We believe in these professions; we put great trust and faith in these professions and we turn to them when we are vulnerable and need good care. These are sacred professions.

What would it be like to struggle against your own humanity? What would it be like to try and save a life and yet fail? What would it be like to try and save a life when the family is wailing next to you? What would it be like to have to tell someone they don’t have a long time left to live when you have just met them earlier in the day? What would it be like to have to help someone process whether they are in fact dying? What would it be like to be screamed at when trying to provide care? What would it be like to
have someone die and then go in a see a patient who is upset about waiting and whose sore throat is the most important thing in their life? What would it be like to imagine that death is beautiful? What would it be like having to explain to a patient that they need hospice? What would it be like having to tell a patient and their family there is nothing more we can do for you? What would it be like to hear a patient tell you, “I’m done.” What would it be like to have to explain to a patient that “we monitor you here not with machines, but with our eyes?” What would it feel like leaving work after seeing five people die? What would it be like telling a family, “your loved one is on watch.” What would it feel like asking a patient if they want you to do everything possible to save their life if their heart were to stop? And what would it be like to care every day for people whose illnesses are terminal and dangerous when you have your own fears of getting sick? These questions give rise to the complexity and chaotic struggles of these places. In what follows, are three ways I believe workers at hospice are attempting to manage the underlying tensions of providing a good death in a place that seems to strip away every bit of humanity. I will refer to the practices as resolutions for managing and rehumanizing care.

The first resolution surrounds the idea of rehumanizing death, which translates to transforming their actual work environment and work practices. The second resolution surrounds the notion of producing a difference, or a different quality of care at the end of life. And the final resolution becomes the active taming of death. Each resolution will be described in greater detail throughout the chapter. Importantly, these same resolutions will be used to illustrate how daily life is experienced in the ED. The resolutions may be similar, but the tension they are responding to is of a different flavor.
Rehumanizing Care and Transforming Work Practices

This chapter will begin by describing each resolution and how each helps you see and feel what it is like to work at hospice by those who work there. The chapter will close by describing how each of the resolutions intersect and shape the goal of hospice. One way hospice manages the tension between an un-stripping of humanity and the promotion of a good death is by rehumanizing the dying process. Providers believe in this type of care so much that many of them believe they have been called to do this work. They have even taken significant pay cuts to work here. Even more, providers at hospice work to rehumanize death by transforming what it means to work at hospice and care for people who are dying. For example, before this hospice took over the old senior residence home, there was a sign on the corner of 9th and Ellis Lane: “Dead End.” Soon after hospice began operation, the city was petitioned to remove the sign. Unable to effect removal due to a city ordinance requiring information, the compromise was a sign that read: “Not a Through Street.”

I start with this example because hospice is a place where workers assert they are different when attending to people who are dying. This was the first story I heard when beginning volunteer training at hospice. They start with this story because it asserts they are different and special at hospice, so much that the street sign needed to be changed. They don’t want anyone to think that coming to hospice is a “dead end.” That language is too intense for a place designed to promote life and living, not death and dying. A “dead end” insists that turning on this street is synonymous with throwing in the towel and giving up. Rather, “Not a Through Street” leaves some space for hospice to promise that
turning on this street is not a death sentence but a place that takes you through death a little differently.

Even more, demanding this street sign be changed contributes to hospice defining who they are by how they are different, especially from a hospital setting. This different way of attending to the dying includes their focus on listening, embracing life, and managing symptoms to keep patients comfortable. The difference they seek is produced through the language they use and the stories they tell, specifically when describing their motivation for working at hospice.

Rehumanizing death deals with transforming the actual meaning of their work and their role in the dying process. For example, Larry, the chaplain says,

A good day is when in that process, during visiting, something opens up with family members or with a patient that takes us to a deeper level, a deep level of encounter, or of conversation about something that really truly is needed in their spiritual life. I look for completion, and for closure on some things.

This passage is interesting in the way it transforms an interaction with a patient into an encounter that takes the patient and provider to a place they need to be. Transforming the interaction into a deep level encounter turns it further into a task where completion becomes something to be achieved. Also interesting is how this encounter attempts to rehumanize death by pointing out that there is something lost and therefore needed for this patient in their spiritual life. And this something becomes a way for this particular provider to regain closure and transform what it means to interact with a patient who is dying by seeking closure, which seems to be doing more for the provider in their attempt to rehumanize death.
Another example of how providers resolve their underlying tension is evident as they attempt to manage the emotional state around death by trying to change the way individuals think about death. For example, Larry goes on to say,

We are not trying to fix something; we’re trying to fix somebody’s way of looking at things. And the ability to do that comes from some place that I am not always sure where that is. But something within me is awareness, knowledge, and experience that I draw on that everything will be OK. All will be well. Whatever the outcome is in our minds, all will be well.

The attempt to fix somebody’s way of looking at things is central at hospice. The acceptance, however, of seeing death as something else takes tremendous work for the provider, patient and family. And it even takes a leap of faith that all will be well no matter what is happening. Believing that all will be right relieves tremendous pressure from describing how potentially difficult and threatening it is to be at hospice. It is as if nothing else can matter so long as we engage others with the idea that everything will be all right. This, too, helps rehumanize death into something not too scary but something that can be managed through a belief that all will be well. Rehumanizing death is also described as part of their jobs as providers as one nurse shared. She told me,

One of the things we do here is we spend a lot of time talking to people. It is one of fortes, so to speak. And it often takes several meetings with them to emphasize and reinforce certain principles or whatever it is that we’re trying to reinforce. To really try to hear them out and to get to know them, and I think in our current structure of how we receive health care that that’s not always possible. So I think a lot of what I hear when people get to hospice is that they haven’t had things
explained to them in that way, or they wish they could have come to hospice sooner.

The focus on listening is interesting for a few reasons and is used again to help produce the belief that a hospice experience is different from another hospital experience.

Listening, however, seems to take a particular path in that even while it becomes a forte of theirs, it is clear that they listen for specific things or listen in order to achieve certain things. The nurse above talks about how it can take several meetings to “reinforce certain principles” but those certain principles are less clear. Listening, too, becomes a way for hospice to distinguish them as different from other forms of care that are familiar to patients and families. And her last sentence underscores that the rest of the health care system is lacking something that hospice has. Some of the principles I believe they are trying to reinforce in connected to rehumanizing death. For example, another nurse describes her way of transforming death into something else when she says,

Part of my job is to help normalize the dying process and make it not so scary for people. It can be a really beautiful time in somebody’s life too; it can be a lot of sharing and really connecting with patients. But most of us white folk just don’t acknowledge it and don’t embrace it like they often do in different cultures.

Normalizing death and the dying process is central to work at hospice for providers, patients and families.

Believing that death is something other than horrific, painful, and devastating helps people cope, especially at hospice. But working to transform death into something beautiful is not easily accepted. In fact, it even becomes difficult for providers too as one nurse shared,
Caring for anybody in a hospital, hospice or nursing home setting is tiring because we are people. We don’t work on clockwork like computers. You can’t take a break when you want to. You don’t always get a lunch break because my role is to take care of patients and have their symptoms managed. I can’t go to lunch if I have someone in severe pain. That is not who I am and why I am here.

This passage really underscores the tensions of transforming the environment at hospice in an attempt to rehumanize death. At the start, the nurse describes how exhausting working in any medical setting is and reminds us all that they are people too who must manage the demands of this kind of setting. She goes on to describe some of the things that make it tiring but she does so in relationship to her role at hospice: to manage symptoms. It’s as if she begins to feel guilty for describing how demanding and exhausting it is because that is not who she is or why she is there. The transforming of the work environment and her role in it works to suppress some of the noticeable challenges of doing this work.

Another example of the struggle to rehumanize death involves the role of emotions and their role in the dying process. In the following example, the chaplain describes how this work is challenging yet describes it as something more meaningful than challenging. He says,

I do grieve. Some patients that we lose, the ones that die, I do grieve because I like to be close and have some chemistry with them. And I have become profoundly aware of grief in people’s lives and resonate with that sometimes. So I cry a lot. And that’s okay. The tears are part of the journey and they are important because they are expressive of the profound and expressive of the loss we all feel
in this life. Life is tough and it’s hurtful and there is a lot of pain in the journey. And I don’t see any reason why to keep from experiencing it. So I think it is important to let myself have the tears occasionally.

Part of rehumanizing death walks a fine line between believing death to be something else, yet needing to explain the reason for specific feelings, like tears. For the chaplain, tears here become understood as an expressive act of the difficulties of life. But it is as if there is guilt in feeling otherwise as the last sentence describes how he lets himself have the tears occasionally. Work is tough at hospice. It is demanding emotionally, spiritually, and physically. But attempting to rehumanize death requires a rethinking of the job and role at hospice. One way that seems to help providers cope with rehumanizing death is transforming the meaning of their job. For example, one nurse shared,

If you love your job and you’re not getting raises or benefits, it’s not tempting to stay. But for some people like me, it is because I wouldn’t want to be at a mediocre job where I didn’t feel passionate about my work. Or if it was a job that was OK and every day was the same. It’s repetitive even though I would be getting more money with better benefits, it doesn’t give the same self-satisfaction as working here.

This is not an uncommon remark for providers at hospice: working here gives providers satisfaction. And being close to people dying brings satisfaction. But in order to rehumanize death, it makes sense that the work environment and their work practices must also be transformed and therefore rehumanized. Believing that death is beautiful and something not scary requires a set of practices to achieve that. Specifically, if those things are to be achieved at hospice, providers must believe in those things and one way
to do that is by believing in their work and believing that their work is satisfying and meaningful. And during the moments where providers talk about the challenges and demands of this work, it often gets reframed as part of the process or an expression of life at hospice.

Rehumanizing death does much for providers and patients to contemplate their role. It also helps transforms meanings surrounding what it is like to care for people who are dying. These meanings around listening, feeling satisfied, believing they are part of deep encounters, become ways for hospice to continue producing this difference that they are indeed different from any hospital experience. Other ways that hospice attempts to rehumanize death is through actual activities such as the hospitality cart or “cocktail cart;” live music and entertainment; music therapy; massage and aromatherapy treatments; pet therapy with visiting dogs and llamas and art classes. Each of these, in turn, help to rehumanize death in ways that honestly distract patients and families from their impeding condition. They also work to organize a different meaning of quality during the end of life. Therefore, the struggles to produce this difference surround the second tension of producing a different meaning of quality of days at the end of life.

A Different Quality of Care

A second way that providers manage the tension of promoting a good death in a place that endlessly strips away part of humanity is through the belief that hospice is unique and different. Even more, hospice talk shapes meaning that somehow this place is different from another medical experience. Although the difference is never explicitly stated, part of the difference surrounds how they organize a particular meaning of quality, different from other places, at the end of life. Part of organizing a new meaning of quality
involves describing how quality of days at the end of life is a unique experience. For example, one nurse describes this by saying,

Being able to really change somebody’s end of life and care from being in the hospital with tubes that they really didn’t want, to be comfortable here, bring them a cocktail at 4pm or whatever makes them happy. Just to be able to give them the quality instead of just more days. Being able to control symptoms seems more rewarding. It’s patients and what you do for the patients. It’s hugely rewarding. I think the whole IDT (interdisciplinary team) approach is huge. Being able to maybe medically we can’t address it, but maybe the chaplains can with spirituality, or maybe we can with music or aromatherapy or being able to use all these tools to help people transition peacefully.

This passage helps illustrate how this particular provider’s talk works to describe some of the very things they believe in and do in order to organize a new meaning of quality. In fact, at times it seems like their particular understanding of quality becomes something to believe in, accept, and act upon in order to think about death differently.

Understanding quality becomes about understanding it as different from being in the hospital with tubes. Because quality at hospice is less about time or quantity and more about what hospice thinks is more meaningful: choice in having things that are perceived to be lost in a hospital setting. Another way quality is produced and organized here is through their focus on a team-based approach that allows them to deliver care that is different and unique. Producing a different kind of quality that allows patients to transition peacefully during the last days is illustrated further when another nurses shares that,
Hospice is kind of a whole different focus because most nursing you’re trying to fix a problem or make their disease better or get rid of the infection, fix their broken bones or something restorative. Whereas hospice, you have to do a whole different mind shift. It’s not fixing. You’re going to let the natural disease progress, and you’re going to manage their symptoms and help them live everyday that they have here. This is instead of just being miserable, depressed, and sick and in pain. It’s a totally different mind shift in nursing but I think it is very challenging and very rewarding.

Not fixing the problem is an important distinction and important struggle at hospice for providers and patients.

Nurses and patients are used to “fixing” or being “fixed” and both seem to struggle accepting something other than fixing a condition or symptom. A better word at hospice might be to “tame,” which means letting the “natural” disease progress as it may. Quality here is again described as being able to help patients and families live every day that they have here, rather than live more days. Further yet, quality is described and understood as something different from another hospital setting experience, which is understood to be miserable, depressing, sick, and painful.

The way providers resolve this tension is further illustrated in the quickness to first describe the challenges of this work, followed shortly thereafter by the rewards and gratifications of the work at hospice. Embracing quality becomes important because it allows providers to believe that their work is not only different but also meaningful enough to sustain, a difficult task when caring for the dying. But hospice clearly affects
people, if nothing else than give those who come close an entirely new perspective not only about death, but also about life.

Part of this new perspective is a result of being at hospice every day and listening, hearing, feeling, and seeing things that happen at the end of life. For example, one nurse was telling me that there have been six or seven weddings in the last six months at hospice. She said,

I mean, driving out of the parking lot and seeing a young woman – also a patient – walking down the aisle… I mean you just don’t see that anywhere. The point is now they are married and that’s what they wanted and it’s fantastic. It’d be better to say I did it than what would it have been like if I didn’t do it? I would rather live with fewer regrets than take a chance. You just see other people happy when you see them make the choice to finally live. Because it is not about dying, it’s not about death. It’s living your life to the very end and living it how you want to.

Again, quality here becomes understood as enjoying what time patients have left rather than trying to produce more days. And in this case, someone deciding to get married at hospice as a patient is a way providers see and feel the difference of this experience, especially around quality of days at the end of life.

Even more, this particular nurse quickly makes sense of a patient deciding to get married because that’s what it is about here, taking a chance to live. And in some ways, deciding to get married and hospice supporting that helps to maintain their belief and practice that this is not about death and dying. Rather, it is about living and having some choice at the end of life to do things that matter to the patient and to the provider. For this
nurse to see a wedding while driving home from work does something to her. After watching it, she said she would rather live with less regrets. Organizing a particular understanding of quality of days during the end of life seems to also translate to understanding quality of days during providers’ lives and those who have experienced hospice too. Working at hospice to produce a different kind of quality at the end of life makes providers aware and reflexive of other things when interacting with patients. For example, one nurse said,

You are going to want to really step up and be a person of your word. If I say I am going to be back in 5 minutes, you better be back in 5 minutes, not 10 or 30. People really value your word especially here. They don’t have a lot of time to argue with you. They don’t have a lot of time in this world to have false promises. You have to be really conscientious of how you make promises.

I felt a similar pressure to really step up as a volunteer. The idea of quality of life and letting someone die more peacefully than at another place, puts certain demands on people who work there to do something different, or even something better.

I, too, was conscious of my word, thinking what if this patient isn’t here next time I come back? Or what if my bringing them Cheetos or a glass of chocolate milk is the last thing they will taste before they die? Do they really need ice in their juice? But what if this is the last orange juice they will sip? Is it necessary I drive to the Safeway to buy organic lemons for a patient who wants to make a picnic in her room and sip lemonade with natural citrus? Did my decision change knowing her time is limited? These become enormous expectations, and it makes sense why quality over quantity matters so much. You have to be a person of your word and patients don’t have a lot of time in this world
to have false promises. As a result, however, these become big commitments to maintain within an environment that pushes and pulls people in different directions about the meaning of life and death. Even though this felt like enormous work and responsibility for me, providers are quick to remind me and others that this is what hospice is all about. In fact, caring here is easy. Specifically, Gerry told me,

All you have to do to work with people at the end of life is listen. I mean there’s other things that you do, but that’s the most important thing, just to listen to people. Just to be with people and not to abandon them and say that you can’t help them because you can help them. So essentially it’s very simple. It’s very easy to take care of people at the end of life. You just have to listen to them.

Listening seems rather straightforward, but for anyone who does listen well, especially to people who are very sick and are believed to be dying, listening empathetically is not always easy.

It certainly was challenging for me to hear the tremble of voices, the mumbles, mutters, silences, stories, tangents, and the soft and shaky comments that they wished they were someplace else. Those voices and stories are hard to listen to. But it makes a difference at hospice, just like their purpose to “not abandon” patients. Whenever a patient is put “on watch” there is always someone, like a volunteer, in the room to just “be” with patients while they die. Listening and just being are not characteristics easily believed to take place in a hospital setting. Therefore, these characteristics become ways to further illustrate how quality is understood differently at hospice. It is a rethinking of what being a provider at hospice means, or even an undoing according to one nurse who said,
Coming to hospice, you are undoing everything you did in nursing. It’s not treat the diabetes, treat the high cholesterol with diet and exercise. It’s eating what you want, you don’t have to take your insulin, or your medications. So you go from one extreme to the next. With pain medication in the hospital, you can have pain medication every four hours, like Percocet and Vicodin. Here it is every one hour. So nurses in the field who aren’t educated in hospice are a little skeptical about giving morphine and high dosage narcotics every hour because they are in that old morphine fears that if they give this dose they are doing to die. Restrictive environments like hospitals and ERs and not very liberal with the pain medication and anxiety medicine like we are.

Part of the undoing of what nurses and providers have learned elsewhere seems less about moving from one extreme to the next as it means producing a different understanding of quality of days at the end of life.

At hospice, a number of things are used to bring comfort to patients and families, including pain medication. There are many ways of understanding how hospice is different, including providers telling you both that it is a whole different way of providing care to being something very easy, if you just listen. The focus on producing a new understanding of quality of days, however, remains the same. Producing this difference no doubt influences those who work, volunteer, visit or care for people at hospice.

Organizing a particular meaning of quality surrounding days at the end of life creates a tension, however, because many patients are endlessly confused and uncertain about what hospice is, but are convinced that it is something different from what they’ve
experienced, and even peaceful and special. Part of the uniqueness gets communicated to the public who begins thinking too that hospice is a special and wonderful place. This is not bad, obviously, but it already positions people to see certain things at the expense of others, like the less beautiful things taking place. But this unique talk in many ways serves as a coping and numbing device for the sadness and confusion surrounding death. More, believing in the uniqueness of the place seems to open the possibility that death is something other than terrible and sad. In short, it helps to tame the wildness surrounding death at hospice.

**Taming Death**

The final way providers manage this underlying tension is through the language they use to tame death or bring death into control. Specifically, the language of religion and spirituality works to tame the wildness surrounding death for patients, families, and providers. As will be clear in the examples below, this type of language provides a comforting frame of reference for many while at the same time providing a rather narrow vocabulary and set of explanations for what is happening. Essentially, this tension becomes a sense-making device for patients, providers, and families. Our language is believed to be limited surrounding death so it is no wonder hospice providers and patients turn to spirituality and religion to make sense of the situation. The point, however, is to understand what using this type of language does for providers and patients, rather than to believe how it should look or sound different.

One nurse, for example, describes how death can look different from what people imagine because she sees God working everyday here. She shared,
Growing up I went through a lot of spiritual paths, being raised Presbyterian then having my mom die, having multiple other people die, I really became agnostic, and not very connected with God or source, or spiritual whatever you say. And through nursing, actually hospice really brought me back to my source, spirit, God. Huge belief because I see it all the time. I see God working with lives, see them talking to angels, or fixed on the light. It’s part of the circle of life, and that’s one thing you’re not going to get out of: nothing that is living ever dies so why be scared of that? If you do have a strong connection with God or some spirituality, I think death is not a scary thing but kind of just challenging.

Believing and seeing God work at hospice helps cope with the difficulties of death and try to bring some control to an uncertain experience. At the end of this passage, Kathy underscores that if people have a strong connection with God or some spirituality, death is not a scary thing. She does admit it is challenging, but believing in something greater than the self helps her cope with death and dying. It is much easier to imagine seeing God working than the devil, even though it felt like that sometimes for me. Our meanings surrounding spirituality and religion provide a more peaceful and comforting reference for death. It helps gives us an explanation to make sense of what is taking place. Just as it has been said before, even working to view death as something other than scary is not to say that it makes the work any easier. One nurse told me,

You have to really go home and feel good about what you are doing. And I think 99% of the staff does. But it can take a toll on your personal well being at home. You go home feeling very sad and depressed about things.
I was no exception to feeling this way as a consequence of being there and my time was significantly limited compared to the providers doing this work. Even more, the tension between taming death and experiencing death is illustrated and felt when another nurse told me,

You deal with death and dying and the potential of death and dying every day. So how do you get up every morning and think about your patients who have done everything right and they are still sick. Or the patients who haven’t done anything right and they are sick. How do you go home and figure I should eat right, I should exercise when I have two patients that did everything right and they still have terminal diagnosis? How do you do that? I think you go home and you love your children more, you appreciate things more. But it can certainly be mentally unhealthy. That’s why we have our bereavement groups that are offered to the staff so we can talk about patients and things that maybe we had a difficult time with.

There seems to be a disconnect between what people say death and dying is at hospice and what people experience as a consequence of being and working at hospice. Part of the taming, then, seems to become untamed in other ways, like people’s personal life where you start loving your kids more, question what you eat and how you exercise.

Some of the other ways language works to tame death is heard and felt during my interview with Larry when he said,

Death is not a mystery to solve but a mystery to be involved in. And it’s just something that in general, as family members experience the dying process, occasionally I’ll get a chance to hear them say, ‘I just don’t know
why she has to suffer so much. What did she do, or he do that he’s suffering so much? Or maybe he brought this on himself anyway. After all he was a drunk, he was a drug user, maybe he is getting what he deserves but it doesn’t seem fair to me!’ And you know those are good comments that someone has to wrestle through with. But it also has this kind of cause and effect orientation that God is devising this onto the person or they’re reaping what they sowed.

This is interesting because at the very moment people are really struggling and wrestling with important questions, these struggles become understood through a cause and effect orientation to bring some control to a set of questions that seem out of control to have to process. Further, Larry went on to say,

What is going on in the dying process is so much greater than that and so much is mysterious. And it’s something to wonder at. It’s going to be painful, it’s not that it is not painful to watch or painful to experience. Although with our medications we cut down on the pain aspect of it.

This passage helps illustrate a contradiction at hospice about believing death to be something natural, peaceful, and beautiful as providers struggle to handle the chaos and uncertainty of the process. They are quick to share that death is indeed painful to watch and experience, but their talk seems to promote another understanding that helps bring control to these other feelings surrounding death. Another way that death is tamed at hospice is illustrated when a nurse shares a recent interaction she had with a patient and their family about death and the status of the patient. She mentioned before how important is it to tell patients the normalcy of the disease and dying process when
sometimes it’s very difficult when providers know it’s not that way. Specifically, she said,

You tell them they are getting pain medication and you have to be honest: your mom, your dad or your brother is getting more pain medicine. We’ve talked to the doctor and increased their dosage. Sure they are physically changing we can see that, which means we are moving along in the disease process. And you have to be the one who kind of says it or they’ll say I know what the answer is going to be can you please just tell me? Are they imminently dying? Are they dying the next day? And you know they are.

After she stopped here, I asked if she does tell the family the truth. She answered,

You do. You know you say, they are on watch and they are imminently dying. They don’t have a lot of time left. But what I can do for you now while you are here to help you get through the process? Like what can I do? I will manage your loved one based on their symptoms to make sure they are calm, peaceful, and comfortable. What can I do for you? Have you had enough to eat today? Have you rested? Make sure you go walk. Can I bring you something to drink? Can I call someone for you? Because once they know it is the end, the end without a doubt, people tend to become very shut down and quiet or very almost relieved.

The passage is interesting in how it moves quickly after saying the patient is imminently dying to focusing on the family or those in the room. Questions about what hospice can do for them are interesting in that they seem to remove the focus for a minute from the patient who is dying to making sure now the family is comfortable.
These honest gestures that work to again try to keep things calm during a time that is often without order. Questions about dying are answered here by way of how providers can bring comfort to family as well. Another interesting experience of how providers tame death surrounds what it means to work here. For example, one nurse described working at hospice through a fascinating comparison. She said,

It’s the most rewarding job I’ve ever had. I put it in the fact of the circle of life. When babies are born, they come into this world at the place, time and family they want to. You’re born to this world when you want to be. And you leave this world when you want to with the people who you want around you or not around you. And it’s the same philosophy. Family is at the bedside when their baby is born, it’s joyous, it’s happy. Family is at the beside when someone is dying too. It’s not joyous and happy but your family is still there from the beginning until the end. So is it less fulfilling when a person takes their last breath or the last person they see or hear or feel or touch? Is it less rewarding than bringing someone into this world as a nurse in OB? It’s the same kind of thing…Nobody ever says to an OB nurse, isn’t your job sad and depressing or awful or terrible? How do you bring someone into this world with all the problems? That’s supposed to be in our culture a joyous, happy time but the dying process is supposed to be a bereaving, sad, grief-stricken depressing time. So we need to change the education to the nursing staff, health care professionals and families that this is not a time of sadness and horrific tragedy.

Comparing death to birth is useful to again bring some control and explanation to the dying process. Understanding death within the circle of life, however, puts much control
on the person to be able to choose when they want to come into this world and therefore leave this world. It doesn’t seem so straightforward.

Would some babies really choose to be born with a degenerative disability or to a parent on drugs? Similarly, would some people really choose to die at age 25 or choose to leave the world not knowing who the people around their bed are? At hospice, it seems useful to understand life and death within broader cultural understandings, like the circle of life. In doing so, it helps to tame what otherwise would be out of control to understand. At hospice, language shapes meanings surrounding death as something other than wild or chaotic. By transforming their care practices that actively seek to produce a different meaning of quality surrounding the last days of life, language here tames death.

Taming, however, does not remove the wildness of it; rather, it displaces the wildness of death so as to not have to manage it directly. In other words, the wildness of death is suppressed through talk, work practices, and even material artifacts similar to the example about the sign, “not a thru street” that opened this chapter. Suppressing and displacing death at hospice enables providers, patients, and families to achieve certain goals. At the same time, however, displacing the wildness surrounding death also constrains them from achieving and understanding other things as well. This matters because through organizational routines and practices, providers, patients, and families are able to tame and therefore death with the messiness of death as well as their own humanity. But what gets lost or constrained when the complexity around death gets suppressed?
The Intersection of Rehumanizing Care Practices at Hospice

The ways of managing the underlying tension at hospice are broad but intersect in interesting and important ways. Death is certain. Moreover, it doesn’t make good sense and is hard for most anyone to understand. But both hospice and the ED staff work to make sense of it. Listening to providers, gives a glimpse into their worlds every day in the face of life and death. Notable, however, are the meanings they struggle with at work and the ways they bring order to an otherwise disorderly place.

Work in both places is difficult, exhausting, and demanding. In both places, though, work becomes organized to bring some control, albeit through different means, to the dying process. Essentially at hospice, providers’ talk works and acts in ways that attempt to rehumanize death and, therefore, their work environment. This transforming of care practices works further to produce a difference in quality of care and quality of days at the end of life. This difference becomes important because through the activities, the language of spirituality and religion, the rewards of working here, seeing someone choose to get married, the ability to listen for eight hours, the belief that caring for people who are dying is easy, and the satisfaction of being with people at the end of life, death becomes tamed. But it is clear that working to tame death at hospice, “lets it out” in other places, like providers’ personal life. Even more, what happens to our understanding of death and life when we work to bring them both under control?

Working here, seeing and hearing the things behind the doors at hospice move people in certain ways. Do you gain a new perspective on death? Do you gain a new perspective on life? Does working at hospice affect providers’ own personal relationships? Does it make you rethink your actions and decisions based on what you
experienced as a consequence of being at hospice? Do you remain the same after being here?

The next chapter will describe the underlying tension ED providers face in light of how they experience and understand their world as they bring order to a rather chaotic environment. The ways providers manage the tension are similar to hospice, but they take a different rhythm.
Chapter 8:

Dealing with the Complexity and Messiness of Death in the Emergency Department

The rhythm in the ED is fast, loud, busy and chaotic. Waiting rooms can be crowded and time can be pressing, yet providers struggle to make a difference in their care. And therein lies the tension. EDs follow a set of organizational practices and protocols. But at the same time a multitude of patients, conditions and symptoms are to be cared for within tight time constraints. Therefore, I argue that providers struggle to manage the tension between following rigid time protocols as well as the sheer volume of patients, while providing care that responds to the unique circumstances of an individuals’ life and health. In short, they struggle to make a difference in a system that endlessly suppresses differences through protocols, checklists and standards. In their struggle, they manage this tension creatively by transforming their care practices.

In order to let you now see and feel how life it at the ED, I have organized their experiences around three ways of managing this tension parallel to that at hospice. First, the providers manage the tension by their own ways of rehumanizing care practices that ultimately transform the work environment towards a specific purpose. Second, the providers refashion a different meaning of quality care that becomes more about time and trying to save patients rather than simply keeping them comfortable. Finally, they manage the tension by transforming care practices and refashioning quality in light of the purpose in the ED that ultimately works to tame death.

These resolutions, like those at hospice, work to bring order to a rather disorderly environment and experience. More, the ways providers manage this tension between individualized care against strict time and patient volume works to control death. Each of
the ways providers manage this tension will be described in greater detail throughout the chapter based on providers’ experiences and stories. I will begin with the third form of resolution, transforming work practices, by starting with a story of delivering bad news in the ED. I am choosing to start here in part because it highlights the tension I am talking about in the ED between delivering care within rigid standards and protocols and being able to attend to the unique circumstances of an individual’s life and health.

Transforming Work Practices

The ED is organized with a specific purpose in mind: bring patients in, fix them and send them on their way. Although this purpose is useful, the ED must be flexible enough to deal with a multitude of patients and conditions. Therefore, the multiple conditions and circumstances run in opposition to simply fixing and sending patients on their way, especially within strict time constraints. To begin to feel this struggle take the following story that an ED doc sent to me verbatim over email that follows:

The 54-year old woman looked tired but she had just gotten off a plane from Europe with her husband. They were sent in by their doctor for evaluation of sharp chest pain and shortness of breath. He was concerned about a possible blood clot in her lung after the long plane trip. I embarked on the usual work up for this including the CT scan of her chest. The busy shift made it impossible to stay on top of all the patients. The red phone from the radiologist rang. The reading on the CT was back.

‘Yup,’ I said. ‘That patient is mine.’ I listened to the reading. My face did not reveal what I just heard. A nurse asked me to discharge a patient who was getting frustrated with their length of stay; an ambulance arrived with another patient. I listened to their report with minimal attention. I was thinking about what I needed to do next.
As I approached Room 6, I could see the middle-aged couple laughing about something he was reading in the paper by her bedside. My pace slowed as I knew that what I was about to say would change their life. My shoulders slumped a little but I took a deep breath and sat at her bedside.

I reached out and placed my hand on her leg. Was it to ground her or me, I wondered? ‘I have the results of the CT scan. This will be difficult to hear.’ I intellectually knew that there was a way in which to prepare the patient but I felt like I forgot it all in that moment.

‘While you do have a blood clot in your lungs, it is rather small and can be treated with medicine that will prevent more clots from forming as your body breaks this one down. But what is more concerning is that your breast cancer that you had appears to have returned and has spread to your chest, liver and bones.’ I stop talking. I continue to touch her leg and I watch her husband move to her shoulder. Her eyes turn from me and well up. Her lip quivers and then the corners turn down ever so slightly. I feel myself let out a breath, not even realizing I had been holding it in.

In that moment, the joy of their trip and the rest of their lives that they plan vaporized. I heard my name paged for the third time. I continued to ignore it. And I just sat with them. ‘I am going to step out and give you some time and then I will return and we can talk some more about this means. I am going to have the nurse get your medicine started for the blood clot. I am sorry to give you this news.’ I step out of the room. I want to turn the other way and walk right out the back doors of the ER. But I round the corner of the nurse’s station and sign orders on a couple of charts and walk into Room 14 to suture a laceration from a glass of wine that broke. ‘Emergent ambulance Room 1.’ I
glance up relieved to see one of the other docs walk in behind the paramedics. I go back to suturing the wound. I wish that all wounds could be managed so easily.

I choose to use this example because it illustrates the burning tension in the ED around providing care in this type of environment. Furthermore, it brings attention to the way providers struggle to care for patients in an environment that demands so much from them, yet doesn’t always support their needs. Even more, it illustrates how the ED is organized to keep providers doing many different things at once, often under strict time constraints. But this example also underscores the struggle for providers to attempt to rehumanize care practices in the ED. In the example, you can feel the tension, struggle and frustration of having to give this news as she is being paged for the third time to go see another patient with a laceration from a glass of wine. This pattern happens frequently in the ED.

Part of the tension surrounds the belief that not many people can really understand what goes on in the ED unless you are there. I think not being able to understand is an attempt to appreciate some of the difficulties working in a place like this and struggling against providers’ own humanity. For example, the same physician describes working here as,

The ED is really quite unique and unless you get to really witness it and witness the personalities and know the people, and know that they are not jerks and not callous, then you start to see it from a different perspective that is all part of how we manage and continue to show up everyday and carry the burden with us of pain, suffering and acute problems.
The passage again works to help rehumanize ED practices. Even the point to mention that providers are not callous jerks sets up this tension around what they are expected to do in the ED and what they experience in the ED. Part of rehumanizing care practices not to believe the providers are jerks often comes out by describing what happens in the ED and what they are called to do. It is as if knowing and hearing some of these stories will help us all re think what it means and what it feels like working here. For example, one nurse shared this story:

The last time I worked we had a 35-year-old girl that had history of breast cancer. She was three years out, she thought she was clear. She came in vomiting and she’s like, ‘I’m afraid there’s a brain tumor.’ And I’m like, ‘well, maybe it’s just a virus. Why don’t we wait and see.’ She had seven brain tumors. And we had to go in and tell this girl you have terminal brain cancer.

Delivering this kind of news is not uncommon in the ED, but points to the searing tension surrounding its environment. Specifically, it is as if providers feel like the ED is a “funny” place to have to give this kind of news. That somehow, it shouldn’t have to happen this way within an environment that is constantly shifting between patients’ needs that are critical to providers and those that seem critical to patients. For example like when a patient came in with a sore throat after another patient has just died. The physician said,

But you know that’s not their problem. Their life is what matters to them and their illness affecting them. Sometimes you have to say something when they’re really rude to you about how long they have had to wait and I have to say you know what, I needed to tend to somebody who is critical and I would hope
that you or when your own family member are in that position, you would want us to make that a priority as well. I am sorry that it doesn’t feel like we are attending to your need but in the emergency room it is truly based on critical need first. But you know, the short translation of that is, ‘fuck you, you know.’ Who do you think you are is how it comes out with anger when you’re tired. It’s like where do you get off thinking you are so important, but you can’t say that. Well, sometimes I do but I get in trouble.

Here again illustrates the challenges of rehumanizing care in the ED for those patients considered “emergent” all the while still attending to those who believe their condition is “emergent.” At some level, the ED seems like a place where “anything goes” and “anything is allowed” to enter. Therefore, it puts relentless pressure on providers to make a difference in an environment that is endlessly different.

Despite the difference, providers still attempt to rehumanize the challenges of working in the ED as well as the frustrations. For example, a caseworker shared how conversations can be difficult with patients, especially patients with drug or alcohol additions. She said,

You feel like you’re not getting anywhere. You’re just talking to yourself, you’re having that same conversation, and it’s frustrating. I’ve had patients that just see repeatedly and it’s frustrating. They are back in here constantly because they’re not doing what they’re supposed to be doing. And I don’t know how to help them.

You can feel the frustration in her voice describe the difficulty of making a difference for patients who frequent the ED. Even more, it is understood within an environment where providers do feel over worked, frustrated and tired.
rehumanizing care in the ED is the steady workflow as one nurse describes a bad day
when she says,

A bad day is when we’re crazy busy and we don’t have enough staff. And we’re
just running our butts off and I get home and my day is still playing in my head
because it was a horrible busy day.

In some ways, this passage relates back to the first example of delivering bad news within
an environment that produces a rhythm that requires stamina and constant shifting of
focus and emotion. Even more, it requires providers to be somewhat autonomous in
providing care as one nurse shared. She said,

If you start falling behind and you have a medication at 0700 and you don’t
document it until 1130 legally speaking if anything were to happen to that patient
court records could come back and say you didn’t, it says you said 0700 but the
chart says 1130. What time was it really done? And there’s ways to overcome
that through our charting process but it’s best to stay on top of it. But to remember
everything that you’ve done and to be working with these patients, one
person’s ringing the bell and this person needs to go for a scan.

Feeling satisfied, then, is difficult in a system as regulated as the ED and a system that
makes providers tired after a twelve-hour shift. Feeling overworked and under
appreciated constrains providers to become emotionally invested in every patient. In fact,
sometimes it is difficult as one nurse describes after meeting a patient during her shift.
She shared,

The first thing he said to me when I walked in the door was, ‘give me a fuckin’
sandwich.’ That was the first thing he said to me. Not hello, not hey, and I said
whoa! I was like, ‘my name is Kelly, and I’m your nurse.’ And he’s like, ‘I pay
your salary, get me a fuckin’ sandwich.’ And I said, ‘no you don’t. I have not
worked for the government for a very long time, and by the looks of you, you
have not paid taxes for a very long time. So you don’t pay my salary, sir. And
the last thing you’re going to get from me talking to me like that is a sandwich.
Now, would you like to rephrase that?’ And he’s like, ‘may I please have a
sandwich?’ ‘Absolutely you can have a sandwich, yes.’ And from then on it
was okay, but it was really hard for me to really care about that man, and care
about whether or not he got home, you know. I got him a sandwich and that was
like the end of my emotional investment in that person.

This passage underscores the difficulty of providing care in the ED, specifically how
invested providers can become. Although it seems as though rehumanizing care practices
within the ED is something to strive for, these practices often stay at a standstill because
of the way the environment is organized towards a specific purpose.

Essentially, the ED is often considered a place to go in emergent situations where
the goal for providers is to do less talking and more caring to save a life. Even more, the
purpose is organized around bringing patients stability and relief until providers decide
where the patient needs to go to get further care. In a sense, EDs can be seen as
“transition” or “saving” places where patients who need critical care come to for
immediate help. Interestingly, however, EDs are becoming more of “dumping places” for
anyone who needs mental, physical, emotional, and spiritual care, thereby putting great
pressure on the meaning of emergency and the organization of emergency medicine’s
purpose.
As a result, this leads to the second way providers attempt to manage the tension of transforming the meaning of quality care. The above examples help you feel and think for a moment what it is like to experience the ED from a providers’ perspective. It’s challenging and exhausting. Even more, a struggle emerges between wanting to provide care that is more customized, unique and humanized, but having to do so within a system organized to achieve efficient, effective and sophisticated care. The latter characteristics put pressure on the meaning of quality of care in the ED, as well as the meaning of quality of life for their own experience.

A Different Quality of Care

Much of the ED is organized around protocols and standards of care. It is also organized so that providers must constantly be moving and multi-tasking. At any given moment, much like some of the earlier examples describe, providers are listening to pages over the intercom, observing and listening to the monitors, watching patient rooms, transferring patients, ordering labs, receiving lab results, making phone calls, communicating with other colleagues, and charting among other things. These tasks, however, are not always well compensated and they make a difference in the attitude and willingness for providers to become involved in what is going on that day in the ED.

To deal with some of the complexities surrounding the complex enormity of tasks that providers perform, they use certain activities, like sarcasm, or make a point of the importance of working with good people to manage the complexities in the ED. Even more, time becomes both a barrier to patient care as well as a way to structure providers’ own thoughts and feelings. For example, when describing what makes a good day a physician shared,
A good shift is if we can have food and we can play practical jokes on each other and for me, we have a lot of fractures that I can fix like where you can have a simple thing where they come in, you can identify the issues and fix it. That is satisfying. It’s not super satisfying to manage chronic diseases because it feels like you’re not really affecting anything – you’re just sort of throwing a little water on some flames and damping it down. It doesn’t feel that when you have someone that sprains their ankle, breaks their wrist and you can reduce it, cut them and you can sew it up. Even if they have a heart attack and you take them to the CATH lab, you identified something and you can fix it. It’s satisfying. Those make for pretty good shifts. And when you get out on time. That’s a really good shift.

The passage helps illustrate the purpose at the ED for many: identify something and fix it. The process of identification, then, becomes a way of understanding what quality care means within the ED. It’s satisfying to be able to fix something and less so to manage chronic disease. Even more, the beginning is interesting that good days come less from making a difference for patients and more about having food and playing jokes on each other.

In some ways, both seem to help cope or distract providers from the complexities of the ED. Further yet, describing a good day by being able to see patients that can be fixed produces and organizes a type of care that finds quality in identifying, fixing and moving on. Later on, this same provider describes further what a good shift is by stating, “when you can intermingle with your colleagues….and maybe you saved a life or many you made a big difference in a family with a patient.” Both fixing and saving are
practices embedded within the organization of the ED. And therefore, all care is directed towards practices that identify, treat, fix, and save. Another task in line with providing quality care is bringing situations that seem out of control, into control. For example, another nurse describes a good shift by saying,

   It’s always a great day when you feel like you’ve helped somebody. When they come in, in crisis and they leave and they’ve had something resolved, and they feel good. Of they have tools to go home with, so that they don’t have to come here and utilize us as their primary source.

Resolving something is similar to fixing something in the ED, and both are satisfying. The satisfaction comes from the way the ED is organized towards a specific model of care where quality is understood a particular way. Part of the challenge, however, is managing providers’ own energy and the energies of other patients. For example, one doctor describes this as,

   There are people with their energies, they tend to dump it on you or they tend to take it out on you. And you are feeling pretty tired and worn out carrying all that energy around all day and I think it is learning how to manage yourself with that as your working environment.

It is important to mention that not only do providers feel stretched to manage patients, colleagues and their own energy, but to manage them within other constraints like time can be overwhelming. One nurse described this challenge by saying,

   Time management becomes an issue. When you’re so overworked and then you feel like you can never get caught up. I have that feeling of if my charting doesn’t look right, my patients don’t look right, everything kind of
snowballs and it makes for a really long tiresome day and the patients end of suffering and so do I. You just kind of see everything around just kind of fall apart.

The snowball effect does indeed make for a long tiresome day. Even more, in the ED, the use of protocols, time constraints and standards move things along at a constant and routine pace. But we know life doesn’t quite work on standards, protocols, routines and checklists. Providers must see anyone who walks through the door. As one nurse was told after complaining that a few patients had come in, “they’re here, they’re go’rna get seen. Check ‘em in and be nice. It’s not go’na matter whether you like it or not, they’re already here and they’re go’na be seen.”

This is standard thinking in the ED, just as it is standard to think quality care translates to providing care that can fix, save or resolve a situation. These standards, however, are not terribly useful for dealing with complex patients with difficult, sad diagnosis, patients and families who need more time to process their experience, or for patients who are dying. Even more, these standards seem to help providers but “bury” some of the challenges of working here. Even more, rules, routines and protocols help to organize care and bring order to a rather un-orderly world like the ED. They also seem to bring some coherence to providers during rather incoherent situations where they walk a fine line between quantity and quality of care.

Even more, you can feel the challenges of providers feeling pulled to stay within the routine because it is expected of them and it is orderly. But you can also feel how they are pulled to make a difference that is different in medical care. This environment produces a rhythm that is all-consuming. It is a rhythm that also helps bury some of the
emotions, fears, wishes and frustrations from working here. Even more, it is a rhythm that moves and steadies to the beats, buzzes, bells, and pages in the ED. In essence, it is a rhythm that helps to bring things under control. Further yet, it helps to tame some of the more difficult and wild circumstances that come in the ED, like patients who are dying.

Following is a description of the final way providers manage the tension in the ED from feeling caught between rehumanizing care practices and providing quality care in an environment that wants to be fixed, saved and resolved. It is no surprise then, that the meaning and handling of death in the ED mirrors the way care is organized and practiced.

Taming Death

Shaping an environment where you aren’t really sure what is going to walk in the door or an environment that can’t be understood unless you witness it is a useful way to think and organize ED experiences. Specifically, shaping the environment makes certain behaviors acceptable, like sarcasm, even around death where it not only is acceptable, but expected to leave the room messy to illustrate that all had been done to save the patient. In the interviews, providers describe death in the ED as chaotic and incoherent. As shown in my own crisis chapter, I experienced it this way also. The chaos in many ways mirrors death in the ED: it is messy and chaotic. But providers do some things that bring some control to their own work experiences. For example, one way of taming death can be felt through the following example about what it means to be an ED physician. She said,

It’s like a job like everybody else’s job. You know you pack your lunch, go in hoping you get a few minutes to eat in peace. I mean, it’s just weird, like I know you witnessed it but sometimes a patient will die and a minute later we are
ordering pizza and it’s not that we have disregard for that person’s life, it’s that – that’s our job and it’s no different that the guy who is a care mechanic who it is tragic for the car owner whose transmission fell out, who can’t afford to replace it and that car is dead. Yeah, you say, we’re talking about a life. I get that but everything is still a job to you and you don’t want us to be – I mean what are you going to do, somebody dies in the ER and everyone has to go home because they are so emotionally distraught so we have to bring in a whole new crew?

In some ways, this passage underscores how the use of protocols and time constraints help bring order to this environment and the care it provides. It’s his or her job, she says, and it’s no different from someone else’s. This reframing of what it means to work in the ED as something not exceptional and incredibly courageous as I think, but rather something ordinary, shapes how care is delivered, especially around death.

Even more, asking to imagine having to bring in a whole new crew organizes the role and place of emotions as something separate from this experience. Knowing that emotions are not accepted or tolerated demands providers to think of their work in a way that helps prevent them from being totally emotionally distraught. Even more, thinking this way makes ordering pizza a logical decision as opposed to something else that might not keep life coherent and orderly. Even more, one nurse describes how dying in the ED is better here as she said,

It’s much better here in the hospital ‘cause you know in the ER you treat them, you get them stable and you move them on. Or you know sometimes
unfortunately they die but you know you’ve done your best and you’ve worked really hard on them.

The language in this passage that providers “worked really hard” on patients could seem difficult if not offensive to hear. But this language fits the ED; it is their purpose. And it also helps to tame a process like death that is difficult to process. This is what they have been trained to do and what we expect them to do.

Providers even mention how time and work load can interfere with caring for people who are dying, as one nurse said, “I think we sometimes have to find the time, even if it’s for five minutes or taking them to a quiet room.” Seconds later, she states “death is a hard thing for most people.” It is especially hard because of the many interests invested into care practices at the end of life.

With that said, let me share a few stories that will help you feel some of the tensions and challenges of caring for people whose interests, as well as the interests of the organization and system, don’t align with providers or patients. Kelly, a nurse in the ED who at the time was working in labor and delivery shared a story with me about how the department didn’t allow recently born babies to be with their parents when they were dying because,

We just took ‘em. They didn’t let parents hold them while they were dying. And there was one day that we were so busy, so busy. I mean we must have had 20 babies in one shift. And that’s a lot for labor and delivery. And we had a pre-termer that was too young to save, and I kind of put ‘em over aside, like we needed the room, so I couldn’t even leave him in the room. Like I had to put him on a table in the sterile equipment thing. And I’m running around and I walk past
the room and I happen to catch him, and I saw him breathing. And I was like,

‘God, I let him die cold.’

This sensitive example illustrates how difficult it is to provide care within a system and an environment full of so much stamina and rhythm. But acting otherwise in a system organized around rules, routines, checklists and protocols is difficult as felt in this example. Even more, this same nurse went on to share another story about a baby who was “deformed” and the nurse told her that her colleague who was pregnant didn’t want to touch this baby or “have anything to do with her.” Kelly, however, said,

‘Let me take care of this baby.’ And I held that baby because like I said to God, I was not going to let anybody die like that again. I wrapped her up, I put a hat on her, and I fed her. They [colleagues] didn’t want me to feed her. And I told the doctor, I said, ‘you know, I can do a lot of things. I understand what’s happening with this baby, but I’m not going to starve this baby to death. There’s plenty of other things that are going to kill this baby, and me not feeding her is not one of ‘em. ‘Cause she’s crying to be fed, she’s hungry. She’s going to get fed. Now you can turn your back and you can walk away and you cannot look at it, but this child will be fed. Period.’

I share both of these examples to help you experience some of the challenges, especially around death that unfold when organizational norms intersect with humanistic norms. No doubt providers just like patients’ experiences with death helps to shape their attitudes towards it. Even more, organizational and institutional norms help shape attitudes and practices, just like at hospice and in the ED. The first example shared by Kelly begins with describing how busy the department was that day similar to the ED where the need
to try to find room for patients, even placing patients on stretchers in the halls, is common as the waiting room and ambulance arrivals are persistent.

Even more, you can imagine feeling the messiness of being in labor and delivery with screaming babies being placed on metal cold tables and people moving fast. And you can also imagine feeling the incoherency and struggle for Kelly to feed the baby that no one wanted to handle in the second example. The standard is to do identify, fix and move patients along, even at the end of life. These standards, however, play an intriguing role around death and dying.

Seeing a room in the ED after a patient has died or “coded” is a mess, literally. But this is common, expected and in line with the purpose of care in the ED. Even more, to get a feel for what it is like to see someone die in the ED, take the following example where a nurse describes how the family is often inside the room now while providers try to save a patient’s life. The nurse said,

Before it was like get them out of the room, we need to do our job. And now it’s like, leave them in the room. And I think if it we’re my kid I’d want to be in the room. But I know enough not to interfere, even as a nurse. But that poor person assigned to me is goanna, ‘why are they doing that? What about this? Can’t they do that? Did they get the magnesium?!’ And I think we’re really sensitive to that, and you get to a point where you just do anything ‘cause they’re, you know, they’re dead, and maybe the magnesium will help. And if the family member wants two amps of magnesium pushed and that will help with their closure, that they felt like they interjected and they got to see everything done, then why not?
Further, the ED room where the patient and family stay are messy according to one nurse because,

   We clean the blood off their face, but we leave all the tubes and everything.
   And we don’t clean the rooms anymore. Like it used to be clean up the room, tuck ‘em into bed, make ‘em look like they’re sleeping. Now it’s like leave the crap everywhere so that they know that we opened the core cart – we went through all this equipment trying to save your family member. You know, and there’s some, I don’t know if its research or just a person’s theory, but there’s an emerging theory that says that family members feel comforted when they see the room a mess.

Providers leave all the “crap” everywhere that was used to save a life so the family knows that they “opened the core cart.” Without such evidence and stuff thrown everywhere, many families don’t believe providers did all that they could.

   Life in the ED is disorderly, just as death is. Keeping death messy and chaotic, however, is a way of taming death within the ED. The story at the beginning of this chapter helped you get a feeling for the intricate balance that is walked between institutional and humanistic norms within the ED. Even more, the subsequent examples of providers’ experience were introduced for you to get a feeling for not only what it’s like working here, but also how providers do work here every day. And clearly, it takes work to do so whether it is transforming care practices that are organized by protocols, standards and routines or thinking of their job just like any other job. In doing so, these practices or “moves” help illustrate the enormous tensions felt inside the ED as providers bare witness to heavy stories, experiences and feelings. And yet they are expected to
handle these heavy stories, experiences and feelings in much the same way as they deliver care: through protocols, standards, routines and checklists.

We all turn to emergency medical care when our ills are severe and not so severe because we know someone will care for us no matter what, when, where. In short, we expect much of emergency providers but too few of us ever wonder what it is like to have God like surgical powers, yet to struggle against your own humanity. What is it like to try and save a life, then be paged to tell someone they have a terminal diagnosis before being paged again to go see a patient with a laceration from a wine glass? As individuals enter EDs with many expectations, emergency medicine is driven by the need to help others where they can.

ED patients have endless motivations for going there. Many come more for reassurance, many come for information, many come to be comforted, and many come for hope. Patients in the ED rely heavily on words, and often these words are used for specific purposes. Words become the way hope, despair, fear, medicine, cure and care are created. Words like “there is nothing we can do for you;” “your liver is going to fail if you continue drinking;” “your husband is an alcoholic and you need to be careful because this a very long and difficult path you are about to go on;” “No, I don’t think you are going to die but you have a very serious illness that needs to be taken care of properly or else maybe you could die;” “we need to admit your son to the hospital because his HIV has gotten more aggressive,” or “you have seven brain tumors” are not easily spoken.

These words carry weight and these words certainly challenge our assumptions and expectations of medicine and care. And these words are difficult at best when the goal is not only to care for patients but also give patients and families, “some vision of
this isn’t a hopeless and helpless situation.” We expect the ED to help each of our unique ailments while expecting those who are providing care to be quick, competent, intelligent, hopeful and compassionate. But they, too, have their own fears of getting ill. And they, too, experience bad days and they, too, have problems with family and romantic partners. And they, too, get tired and sick.

In the ED, like in the hospice, questions about illness and health and to a lesser extent, life and death dance together intricately. Furthermore, a set of tensions seem to be organizing care in both settings that help refashion care practices in a way that brings some control to the disorder and incoherence that beats and breathes at each site. Although these tensions surrounding providing humanistic care within institution norms take different forms, their goal to tame death remains the same. What is interesting, of course, is how taming becomes part strategic, part routine and part improvisation for understanding the meaning of death and also life. Even more, the purpose of this project is not to argue that the way these places are organized is inherently wrong. Rather, my purpose has been to show and tell the stark difficulties of these places. The stories of providers at both the ED and hospice need to be told, for in them, we all must wonder – is this the best we can do at the end of life?

These ideas will be developed further in the final chapter and even more, I will describe how the way death is being produced at both places enables and constrains critical understandings surrounding care practices. The next chapter will also describe how packaging and managing these tensions make some of them easier at both hospice and the ED, while making others more difficult, like supporting and hearing the voices, stories, and fears of the people behind the double-glass doors at both sites. And finally, I
will address why accepting a system that embraces chaos is so difficult to do, but also what would be needed for both places to accept a system that lives with chaos instead of trying to manage it.
Chapter 9:

The Enabling and Constraining Character of Rehumanizing Care

The last two chapters described how these sites are experienced and understood by the providers who work there. Even more, the last two chapters have detailed the tension of providing humanistic care within and against institutional norms. And finally, the chapters developed three specific ways providers overcome this tension that together, ultimately tame a process that would otherwise be wild, chaotic, and uncertain. Through taming, however, providers are doing more than rehumanizing their care practices; they are actively producing meanings surrounding death that are defining how we can and should understand death and the way it is handled at the ED and the hospice. Therefore, the role of this chapter is two-fold. First, I will describe how our understandings of death are being formed through the accounts and stories from providers. Second, I will outline how in producing and defining meanings surrounding death, providers’ talk is simultaneously enabling them to smooth over the complexities of working while at the same time, talking in a language that conceals them and their work from critical engagement.

There is an inherent tension at the ED and the hospice. On the one hand, their jobs demand that they be routine, standardized, sophisticated, and effective. And on the other hand, their role is to heal and provide humanitarian care in a demanding and chaotic setting. Embedded in these contradictions, however, are a number of suppressed conflicts and opportunities. Therefore, rather than simply showing you how providers manage their challenges, I will describe what these practices are doing. In order to detail what providers’ talk and practices for taming death are doing for the meanings surrounding
death, I will return to Gerry and Susan’s narratives from chapter one. A return to the narratives is also a return to the role of language and discourse in the production of death. But first, let me say a few things about language and discourse.

Providers at hospice and the ED use their creativity to deal with the messiness of both places. Listening to their stories and accounts from the previous chapters, emphasizes that their stories need to be told and listened to. In doing so, we realize they are saying much about how death is handled and should continue to be handled. Yet their stories and accounts about death have implications for the meaning of death. Providers are very creative in handling death that at times works to decorate death as something unique, hard to understand without being there, and very difficult to handle. But their attempts at decorating death or care taking in general conceals conflicts from occurring and therefore, suppresses meanings from being contested around death.

Conflicts become suppressed in a variety of ways, especially around death. One conflict being suppressed is trying to make a difference in medical care embedded in a system that in remarkably routine. But this conflict becomes concealed through their language promoting that life in the ED and the hospice is different from any another place. Even more, this conflict becomes suppressed through the stories they choose to tell that reaffirm, if not naturalize for them, that what they are doing is special, different, and unique. Further, these moves suppress further the ability for any one to critically engage what it is like to work at these places.

For example, at the beginning of this project I discussed how many believe that the U.S. is death denying. Through providers’ accounts and stories, however, it is clear that we are not necessary death denying, but we are indeed fearful of death. In chapter
six, I wrote about my unspoken anxieties of dying, and even the possibility of dying, or someone close to me dying. When we fear, as I argue providers are doing like me, we often stigmatize and shun death, if not sometimes even trying to destroy the very possibility of death.

The first narrative, if you remember, comes from Gerry, a nurse practitioner at hospice. And recall that I have taken these passages from an interview with her; my questions are in regular font and her words in italics.

Consequences of Talk at Hospice

What’s a bad day here? Well a bad day is when I can’t help somebody in the sense that they don’t seem to understand what I am saying or maybe the team isn’t able to communicate effectively – I mean that is really one of the key challenges with our role is what we say and what people hear. This passage details the way the hospice begins to construct a particular meaning and a particular experience about death. Defining a bad day as when patients don’t understand providers’, positions us to accept and prioritize that the providers’ understanding must be prioritized. Imagine if a bad day was defined by feeling frustrated they providers couldn’t understand patients. This would immediately prioritize a different kind of experience. Further, communication is understood through its effectiveness in communicating a message to the patient that they are not hearing in a way the hospice wants them to. The patient here is essentially being blamed for not being able to understand why they are at hospice “effectively.” Imagine for a moment the perspective of the patient who just arrived to hospice after receiving a terminal illness with not much time left to live. Further, imagine you’ve been admitted to a place that has quickly been defined as your new home with not many of your belongings or familiar
surroundings. And imagine what it would be like to hear that this is a place different from any other hospital setting you have been to as you stare out the window to the empty bird feeder lying in a white sheet in an uncomfortable bed. Would you feel understood? For the patient, this might be one of the key challenges for coming to hospice, not feeling understood and not wanting their experience to be defined so quickly for them.

And if we are speaking different languages, which can often happen at the end of life, then poor communication is go’onna make for a really bad day. And it happens in all different shapes and sizes. Each situation is going to be different but if you have a day where you are just not able to communicate openly with another person, it’s going to make for a really bad day. What do you mean by different languages? Could be a cultural difference. Could be just a knowledge deficit about their disease process. It could be in the form of – maybe they are just in a different place of their illness, their journey – they might have an expectation that is not aligned with hospice necessarily. Not everyone comes to hospice knowing what hospice is or understanding what hospice is, or being ready for hospice. So we’re not here, I’m not here to make them ready but to meet them where they’re at and to see how I can help them best. And that may be staying here on hospice or it may be finding what’s in line with their particular goals and values.

The paragraph begins to decipher the way language is strategically used and how everyday terms shape interaction norms. Furthermore, everyday terms describing what hospice does, is often clarified by describing what it does not do. For the most part, what is identified in this paragraph are external constraints like, “different place of their illness,” or “not everyone comes to hospice knowing what hospice is.” Even more, we hear a unifying and colonizing voice speaking about hospice in general terms, not in
specific terms about a particular setting. Further, medicine here comes across as having choices or “meeting them where they’re at,” but the options of “staying here on hospice” or “finding what’s in line with their particular goals” leaves out a plethora of other options or alternatives that are not discussed. It is as if there is variety in choice, but in actuality, it is more like an illusion of choice around end of life. Further, this paragraph already presumes a hospice frame that “place” at hospice matters. The last sentence doesn’t explicitly say options, but Gerry’s language already frames a particular understanding that there are options for patients.

This enables her to explain how hospice is a unique environment. In essence, she is producing a difference for why people come. She never describes what the difference is but more importantly, in asserting they are different closes off examination and discussion about them. Additionally, Gerry refers to these as different languages, which has implications for how we understand communication at hospice. She states how speaking different languages often happens at the end of life as if to excuse if not conceal what some of the differences are. And stating that this “often happens,” she begins to naturalize this understanding rather than leaving it open to critical engagement.

Feeling misunderstood for both provider and patient becomes understood as speaking different languages at the end of life. But actually, it is less of different languages and more of a difference in the implicit values and beliefs of both patients and providers about what a fair death would look like for example, and what providers’ role is in that. Finally, calling these “different” languages underscores a dominant theme throughout hospice that things are different and unique, including the language around life and death. Consequently, defining languages as being different closes off discussion
or examination and instead begins to normalize and naturalize a belief that different languages really do happen at the end of life, thereby keeping them unquestioned.

What’s important for this kind of work? *First and foremost, you are a human being so don’t forget you are a human being! You have to be genuine. I would say listen to other people as much as you can and when you find that you are not able to interact with people anymore whether it is on that given day or that you have to take care of yourself or you’re never going to be able to take care of other people. So care for yourself, be genuine.*

What is produced here is a fascinating orientation towards death that is about “being who you are” as if nothing else could matter. Embedded in the talk, however, is a push for authenticity and genuine interaction that includes moments that point to the difficulty of this work. For example, “as much as you can and when you find that you are not able to interact with people anymore” defines limits. Caring for the self becomes just as important as caring for other people. But telling people to be genuine is in reference to knowing that you are a human being that has limits and you should not forget that. It is as if her use of language is trying to infuse a sense of humanity for this type of work that tends to strip away in this unique environment while reminding us all of our inherent limits as human beings. We miss critical important information about working here when it is described like this.

*You have to be really empathetic. You have to be very compassionate. You absolutely have to have a good heart, which probably encompasses all of the above. I would say the primary characteristic that you really need is to be an empathetic person.*

*But at the same time you have to realize that this is the patient’s and family’s experience*
and not your experience. So that they – the patient and the family – are essentially the ones that are going through this and you are trying to guide them.

To say someone needs characteristics of empathy and compassion, demands vulnerability. Even more, using these qualities orients us to think of hospice as truly kindhearted. But interestingly, the next move to remind someone that this is not their experience is complicated because after all, it is difficult to be empathetic without somehow becoming part of another’s experience. Empathy demands a sense of being part of something or someone involved in your life that asks people to feel, suffer, and celebrate similarly. It is a coming together to feel, suffer and celebrate in a similar way. Providers are involved in this experience, too. But here providers are guides in the dying process, not players involved in the experience. They are guiding patients to a particular feeling and experience of end of life. And when they cannot, or when patients become resistance to accept this experience, providers describe this as a bad day or a frustration because of the different languages at end of life. When patients resist this experience, providers push back, feel that they aren’t communicating “effectively” and this makes for a crummy shift. Because when patients resist, responsibility shifts away from a routine hospice death where other figures, including religious figures take over. When patients resist, however, providers begin to feel as though they are not in control of someone’s death until they can communicate in a way where patients “buy in” to this way of dying.

Are there are any barriers that get in the way trying to guide patients and families? Yes, in fact, the day-to-day nonsense I like to call it, just the interruptions, the flow of events, and the work environment. Essentially, when I talk or meet with a patient and the family, I try to immerse myself in that experience and really close everything else out and
not be thinking about what else I could be doing whether it's with another patient or whether it is something personal, to really give 100% when I am with that patient.

Recall, however, that Gerry just reminded us that we are human beings with our own limits and to not forget that. But here, she describes how she tries to get close and immerse herself. Similarly, she just described how important it is to be empathetic but to know that this is not your experience, but the patients and families. Here, she is telling us again how important it is to be 100%. These past few passages underscore glimpses of the difficulty of working here. Hospice promotes empathy and promotes life and living, which is why Gerry oscillates between coming back to the mission of hospice, while also exposing what happens when patients resist this particular experience. Even more, interruptions become barriers because in many ways, they disrupt the routine ways of care taking, if not even dislodging providers’ ability to think for a moment about something different.

Further, the way Gerry describes her experiences with patients with language like “immersion,” “empathy,” “close everything else out,” and “give 100%,” attempts to define a hospice experience as something different where these activities are normal. But how can we begin to talk about the dying experience at hospice when each experience is so unique and special and “heavy?” We can’t. Because these experiences become defined as so deeply personal and authentic that it conceals any one from talking about these experiences in any way other than the way hospice is doing.

*Being a nurse to me is something really special. It is something that is very personal, it’s just a very unique relationship that you have with another individual that you aren’t always able to share in other locations or professions. And it’s something that,*
being a nurse to me it’s more about, it’s not just the medical piece or the health piece – it’s really relating to that person in a way where they feel open enough to disclose things that are very personal and private issues. And you have to earn their trust, you have to earn their relationship, you have to you know just because I am a nurse doesn’t mean you have to tell me everything about you.

Working here is something to be proud of because it is a way of relating to someone in a particular way. Her description of what it means to be a nurse describes a rather prestigious and sacred profession. Not everyone experiences this extraordinary relationship. Even more, there is something sacred about it that is not “able to share in other locations or professions.” Further, she describes being a nurse as something more than the medical role in the relational qualities in healing professions. They are in a particular relationship with someone in which medical care is delivered by a special, humanitarian professional. If you believe in this philosophy, it supposedly will guide you to some place better around end of life.

Are there specific things that you do with patients? Yes, of course. I try to just get to know the person. It’s hard because there is a blur between personal and professional but I just try and engage the individual just talking with them, not just coming in and just focusing on the issue at hand. I mean if I come in and say how is your breathing today? If that is going to be the extent of my relationship with a person, then that is probably how they are going to disclose things to me, reveal things to me and that’s all our relationship is going to be. For hospice, where we all wear multiple hats and even though I assume the medical provider/nursing piece of their care, I can’t shut them down if they want to talk about something else because that is not what it is all about. So I essentially just try
and get to know that person, try to get to know what they are comfortable revealing to me and go from there. Hospice care is difficult and people often don’t have a good sense of what it is. How come? Well, there is a real interest coupled with fear. It’s a real conversation stopper at times. There are a lot of people that just say, “oooohhhh.” My family and friends will still ask me but there is still kind of a veil that comes over them when they talk with me about how are things at hospice, their voice changes and it’s serious stuff and I realize in conversation with them how open I have become to talking about dying and the end of life and how comfortable I am on a professional level with discussing dying and end of life issues. Do they understand what you really do? A lot of times, for example, my family and friends will ask me exactly what I do and they have an accurate impression. My brother, he doesn’t live in town and he has known that I have worked as a nurse practitioner at hospice and he kind of skirts the issue a little bit. You know I don’t think he fully understands what I do.

Hospice as a “conversation stopper” is not surprising. Just the words can close communication because they mean something strong, yet mysterious to so many of us. But why can’t we talk about hospice like providers do? She mentions how “comfortable” she has become talking about death but there seems to be a disconnect with what providers say and what patients (and I) experience. Her talk immediately tames the seriousness of how people’s voices change when she mentions she works at hospice. But talk at hospice tries to produce a different kind of death that often runs in direct opposition to the dominant discourses surrounding the place, its smell, its philosophy and its name. But the place, the smell, its philosophy of care become concealed or closed off through the tremendous work their language is doing to produce such a unique
experience at the end of life that providers, patients, and families begin to take on as their own, without question. Gerry mentions how comfortable she has become talking about death. Habits are comfortable, just like talking about something in a particular was for so long becomes comfortable. Feeling comfortable talking about death begins to sensitize even the surroundings around the place. But these surroundings to any “naked eye” or un-socialized eye are tremendously visible and difficult not to see. But language conceals these things from not only being seen, but never critically examined because the values embedded in hospice about life, living, and authenticity take priority thereby making certain meanings visible and believable and not others.

Why do you think this problem exists? *I think a lot of it is very emotionally charged. You know each and every one of else has known someone who has died and for most people it kind of elicits a painful emotion, probably a mixture of feelings. And so when people talk about dying, especially if they don’t have the professional perspective, it becomes a very personal event and it’s kind of; they may be respectful, they may feel a lot of gratitude towards hospice professionals either in the past but for a lot of people it really isn’t a pleasant experience so it is something that makes them very emotional and not necessarily in a good way.*

Professionalism here is intriguing, because for her it makes reality easier to accept, rather than allowing it to become “a very personal event.” But death is personal and unique! Her talk almost disregards feelings and emotions at the end of life that make it an unpleasant experience. What’s even more interesting is how having “the professional perspective” is producing a new meaning of professionalism that embodies being in relation, fully immersed, taking care of yourself and just trying to get to know
the person. She says how non-professional people talk about death as a personal event. This illustrates how hospice does not avoid death, but is an interesting plethora of competing voices about death. Their talk sets up the incredible difficulty of working here, and the real pleasures of working here. More, this kind of talk works to humanize who they are and how they identify themselves during a dehumanizing experience. We hear incoherent, contradictory voices about death and hospice that begins to leave us all at a standstill of wanting to examine them because what we often thought death to be is being defined for us differently.

This short narrative exposes an interesting way of packaging death and putting aside meanings that compete with the philosophy of hospice. Even more, this packaging of death gives us glimpses of the real difficulty of this place and the real difficulty of this work. Even more, we hear distinct calls to the sacredness of their professions but wonder whether they are still sacred in an environment that is remarkably routine yet through stories they tell, try to make it not routine. Consequently, providers seek to transform what otherwise would be routine through language that for the most part is sealed off to others who have not seen, felt, and heard what their world is like. More specifically, the packaging of death becomes a way to code language surrounding death. Essentially, this coded language produced a space of taboo talk. It is not that death is not talked about, but rather death is talked about in a very unusual and coded way that tries to make the “non-beautiful” parts of death, invisible.

For example, hospice codes death through their language use around empathy and authenticity that shapes a particular meaning about care taking. And the ED codes death through their use of language that asserts that no one can understand the ED without
being there. Consequently, this coded language becomes accepted, habitual, closing itself off from critical examination. In short, coding language around death makes it so no one, in fact, has to face the fear of death because through coded language we have essentially worked to stigmatize dying experiences as being nothing but routine.

Consequences of Talk at the ED

Interestingly, these same moves and consequences of talk are not unique to hospice, they also infuse the ED. Let’s now return to the earlier narrative in chapter one from Susan, an ED physician. Again, I will go paragraph by paragraph to describe not just what she is saying, but what is being done.

It’s like a job like everyone else’s job. You know you pack your lunch, hoping you get a few minutes to eat in peace. I mean, it’s just weird, you know sometimes a patient will die and a minute latter we are ordering pizza and it’s not that we have disregard for that person’s life, it’s that – that’s our job and it’s no different from the guy who is a car mechanic where it is tragic for the car owner whose transmission fell out, who can’t afford to replace it and that car is dead. Yeah, you say, but we’re talking about a life. I get that but everything is still a job and you don’t want us – I mean what are you going to do, someone dies in the ER and everyone has to go home because they are so emotionally distraught so we have to bring in a whole new crew? That is a hard thing for people to get. It’s not that we are not compassionate – we’ve been doing it for 20 years and our job goes on. As soon as you finish with this one person who died and console their family, now you are 15 people behind and they are all mad as hell at you.

Comparing her job to a car mechanic informs our understanding of the ED. For one, it immediately transforms the place into something normative and instrumental: this
is a job with routines that we follow. As soon as you finish, you have 15 people behind and they are all mad as hell. This sounds like an uncomfortable place to work. Further, she goes on to ask whether we expect them to bring in a whole new crew after someone died because they are so emotionally distraught. In so doing, her language tries to normalize work and life in the ED. She “packs her lunch” and “hopes to get a few minutes to eat in peace.” But we know ED providers talk much about the mystery and uniqueness of the place, but, like the hospice, it is still a job.

Even though they are dealing with individual lives, “it is still a job.” The implications of referring to it as just a job provides a glimpse into the real routineness of their work. Even more, the moment that glimpse becomes visible she follows with a statement that asserts again they are different. It is hard to imagine a situation where every one would be so emotionally distraught that they would call in a whole new crew. But in saying this, she closes off examination to her job because after all, she is dealing with a life, not a car. More, her language pulls you near in a way that makes you feel bad for providers. But the moment you get sucked into their thoughts and feelings as I did is also the moment critical examination stops and things become accepted, rather than questioned.

What makes for a good day at work? *I think the personalities in the ER – different nurses, and other docs you are working with – is definitely one of the bigger variables. If you’ve got the right mix, every one has good energy, it’s funny, sarcastic, playful and we can diffuse a patient’s energy with each other. The patients that wear us down are the patients that are demanding, have ridiculous expectations, like I have had this for fifteen years and I have seen 10 specialists and I am here Friday night at 10 pm and I expect*
you to have an answer to why this is going on. That can be absurd and sometimes you can let it roll off you but sometimes patients are so in your face and make you in your weak moments really defensive and engage that behavior and that makes for a bad shift.

Here you can feel how she lets things “roll off” and finds energy in each other in order to cope. Even more, you pick up on the real changes of this place. The way it is said comes out as a struggle and you can even feel a sense of the difficulty in this work. She sounds worn out when she talks about how patients wear them down. Finding play and fun in other colleagues to diffuse a patient’s energy reminds you of the struggle within this talk, and therefore the struggle of this work.

And then there are other things in the mix that make for a bad shift – last night it was a bad shift because there were a lot of patients that had a lot of sad diagnoses, like one woman came in, had breast cancer 15 years ago, she had bilateral mastectomies, they didn’t recommend chemo and radiation, they said it was not called for it was such a small tumor and she comes in with a complaint of a herniated disc kind of symptoms and has enough neurological symptoms that I did an MRI because she had lost her reflex, she had lost some bladder control, and sometimes that means you have to do something surgical. Got an MRI and she had boney metastases throughout…and you know it was like taking all the wind out of her sail and I think she thought it was never something she’d ever worry about that came back …you know that is hard, it’s hard to give somebody that diagnoses, it’s hard to feel like in the ER you’re doing anything but dumping all this horrible information on them saying, alright, why don’t you follow up with your doctor, we need the bed, there’s 15 more in the waiting room.
Again, it sounds like someone just took the wind out of her sail. Describing the process of giving bad news is tough in the ED and you feel it in her talk how much this work is getting to her. You can feel a sense of struggle in trying to help and do something different in a system that continuously dumps bad information on people. Even more, it is like the difficulty of this kind of work sucks the energy out of these professions and the difference they are able to make in our care and health.

*You know it’s like you can’t spend enough time with them – you know it’s not like they need you to spend more time with them that minute because they need some time to take it all in and sort it out, but the ER seems like a funny place to be handing out that info. So, bad diagnoses can wear us down because we are people too you know and we have our own illness and fears about getting illnesses or it might remind you of a friend you had that had something and it just sometimes gets really personal and it’s hard to keep up your defenses and it’s not to say that you are like a wall and impervious to all that is around you but I don’t know that people get that. At some level we have to have the wall up or we would be consumed by horrific diagnoses and sadness and other stuff we do.*

What is interesting here is how the everyday terms identify internal constraints like, “bad diagnoses can wear us down,” or “we have our own illness and fears about getting illnesses.” Furthermore, the notion of “place” is interesting here like, “the ER seems like a funny place to be handing out that info.” The physical place of the ER becomes its own norm or way to organize what and how things can be discussed and not discussed. Also, talk here includes unifying terms such as “we are people too.” Because the framing is turned inwards onto the self, medicine takes an interesting role as people
are putting up “defenses” in order to not be “consumed” by “horrific diagnoses” and “sadness.” In other words, these interaction norms point to the work that medicine and physical space demand of individuals thereby highlighting other underlying logics at play. These terms carry inherent ideological properties like the physical place of the emergency department that organizes how care is administered. Even more, the ideological properties of place help organize emergency medicine’s own set of tensions, strategies and protocols of how to accomplish the work with the language being used. Her language simultaneously distinguishes what is acceptable and not in the ED.

*Having to try and save someone’s life while family are walking right next to you, is not an easy task. You have to somewhere put it aside and though you know it hurts – you’re trying to help somebody and I guess that is the hardest part that in medicine, at some point you have to figure out how to manage it and if you don’t find a way to let it out later it starts to make you a bitter, cynical, burned out doctor that takes it out on people and that is the end result that patients see and say what an ass that doc is, but they might not appreciate all the pain and suffering we’ve had to bear witness to that has taken it’s toll on us, even though we signed up for it. It still is hard and they don’t teach us how to manage that. And there are conferences and lectures on how to handle the difficult patient or whatever but it is not really something we embrace. You know it’s not like, hey look what I am going to. It’s more you take it on because somewhere down the line you learn you’ve got to do these things to save yourself.*

Reading this you can imagine just how much pain and suffering she and others have had to witness. Have providers always experienced so much pain and suffering? Her language highlights how life in the ED feels like they only give interventional treatment
before moving on to the next patient. But her talk also underscores how she hopes care could be different. That is, how it could be more faithful, honest and sacred. In short, she does a beautiful job of producing and defining meanings surrounding how death is handled in the ED.

The language used by both Gerry and Susan produces particular experiences of the way death is handled. Further yet, their talk enabled them to smooth over the complexities of working while at the same time, talking in a language that conceals them and their work from critical engagement. The latter is where I will turn to next.

Coded Language Around the End of Life

The first part of this chapter has focused on what language enables providers to do around end of life. This part will focus on how their same language closes their work practices and experiences off from critical engagement. In doing so, important conflicts are being suppressed and lost surrounding how meaning is being produced at the end of life and how different choices might become thinkable.

The last chapters have illustrated how providers produce a particular experience for care taking around the end of life. Part of understanding this experience is understanding how their worlds are organized around the tension of providing humanistic care in an environment that is uncomfortably regulated and routine. The tension for the most part is irresolvable, yet it is solved in some ways through the rehumanizing of care practices and even in the stories they have chosen to tell me. Why, for example, did the nurse tell me about saving a baby so that the baby wouldn’t die cold on a metal table? Or, why did the doctor at the ED choose to tell me the story about the couple from Europe and the laceration from the wine glass? Both of these stories happened months if not
several years ago. Why are they still telling them? Why when asked about delivering bad news, the doctor told me this? And why when asking about how they have been socialized to think about death, the nurse told me a story from several years ago about not wanting to let a baby die hungry or cold? The stories help them cope. They also help them justify their existence and give them meaning in an environment remarkably routine. These stories seem to be doing something further yet.

Providers solve this tension partially by suppressing a part of what they don’t want to necessary deal with: the out-of-control nature of death. The stories become one way of not having to face the complexity of death through the translation of narrative rationality to technical rationality. Even more, providers’ language promoting that they are different, unique, and are organizations that you can’t understand unless you are there becomes another way of not having to face death. And further yet, these moves illustrate how quick stories, even complex stories, become understood through an actionable list. These moves, or activities that take place serve as a blockage, thereby closing off opportunities for things to be done differently.

Discursive Closure at the End of Life

Committed to a critical and dialogic approach from the outset, this project is concerned with the way language and meaning becomes distorted. Is it not enough to say that providers’ practices tame death. Rather, I want to share what happens when death becomes tamed and I want to share what happens when organizations endlessly produce meaning that they are different and unique from others.

For the most part, I have been working with competing discourses of care. But embedded in society are also larger and more dominant Discourses that promote an
orientation toward life that embrace living the fullest until we die. Similarly, these Discourses promote saving and fixing a life at all costs, which has become routine, standardized, and naturalized. The ED and the hospice organize their practices around these discourses and are essentially being organized by these same Discourses. From chapter one, we know that Discourses are ideological and infused with implicit values that prioritize what kinds of choices become thinkable, and which choices are made. And of course, a host of other values, other meanings, and other choices remain invisible.

Other values about how death should be handled, or where death should take place, or how much pain we are willing to bear get suppressed when language tames death. Providers do this too. By taming death, they are not simply mediating their experiences; rather they are actively suppressing something that becomes too much to “stomach” every day. In essence, taming death through their language begins to shift some responsibility away from them to the purpose of the organization that is to save and embrace life until the very end. Even more, what is happening by transforming the uniqueness and complexity of death is that the meanings and practices surrounding death are being reproduced. In doing so, death is becoming routine, standardized, and normalized. Through routines, of course, making choices and decisions also become routine, standardized, and normalized embedded in systems, organizations, and Discourses deigned to save a life until the heart stops. In doing so, what is being suppressed and blocked is the un-spokenness of the real fear of dying or getting ill.

The way death is handled, however, depends on the way language is being used, and our access to language. At the hospice and the ED, language is used to smooth over the complexity and difficulty of their work to make life easier. Their lives are routine at
these sites even though the stories they choose to tell, and not tell, or the things they want you to see, and not see, become ways to expose the values embedded in their talk to think that it is something other than routine. Stories about seeing six people die for example, or watching a hospice patient get married at their chapel, or sharing a story about telling a patient they have seven brain tumors are all stories that don’t happen every day. Yet these stories serve as reminders that their work is different, important, and unique in an environment organized around protocols and routines.

Further, providers believe in stories. I believed in them. They take them on as if they just happened a few days ago. I took them on as if they happened every day. Stories blocked me from seeing things, however. And I imagine they block providers from seeing things as well. Stories, checklists, and protocols don’t fit the uniqueness of a human life. As a result, providers use these routines to not only tame death, but to hide behind them. Think, for example, how often providers at both places promote that they are unique and different. What does this do for them?

Promoting that the ED and the hospice are different and unique from other settings and saying that you can’t know what they are like until you are at them, immediately makes it so we can’t talk about them. Claiming uniqueness seals them off from any really critical engagement. Spending time in these places, however, I quickly realized that there is nothing quite unique about either one even though they continue to say they are different and that you have to be there to experience them or else you “won’t get it.” Even more, in claiming uniqueness, providers’ experience becomes subjectified and also sealed off from critical engagement. No one is supposed to ever really be able to
understand these places or providers outside dominant Discourses that promote the role of providers as god-like-figures with infinite power and knowledge.

Their experiences become understood as so deeply personal and painful that no one believes they can ask, or understand them. But providers do talk. They freely tell stories that make people curious about them. They choose to share stories that make others impressed with their power, knowledge, and compassion in these environments.

Interestingly, the first few days I observed the ED I was taken up the ICU to watch morning rounds. It was terribly uncomfortable and perhaps they wanted me to see and experience the real pain and suffering of these places to begin shaping everything I saw or heard. Similarly, when I first started observing the hospice, I was invited for three days in a row to “get the whole hospice experience.” I was initiated, or disciplined, at the very start to orient myself towards seeing and feeling in a particular way about how death is handled at these settings. In short, I was learning the language and learning the code.

Further, sealing their experiences and stories off from others we all in a way are slowly stigmatizing these professions by not critical engaging them, their experiences or the system in which they work in. Claiming uniqueness seems to constrain all of our ability to talk with providers, discuss choice options about death, and understand both more meaningfully. Instead, claiming uniqueness is sealing off so much through a funny and coded language about death.

Both places are producing and colonizing their own spaces of taboo talk about death. There is not silence around death but rather a river of voices being spoken about death, albeit in ways that are coded. The coded nature of providers’ talk becomes the very way they handle and organize the tension surrounding death. In trying to solve the
tension of providing humanistic care in environments that are uncomfortably routine, providers speak in a language that is accessible, routine, and familiar to them.

Further, taming death allows providers to not face the wildness of death as it is believed to unfold. But what is happening is that providers are reproducing a very particular routine way of handling death at both the ED and the hospice. The handling of death is routine thereby closing off a plethora of other choices that could be made. Even more, the routine ways of handling death are leaving much un-spoken. The invisible and the un-spoken must be heard in order to bring some kind of contestations to meanings surrounding death so that stories do not become our only way of encountering difference in environments that suppress difference.

The values embedded in these routine choices are exposed through Discourses and the ways they prioritize what kind of language to use, what behaviors are acceptable, what feelings are right, what choices are available to make, and what choices we should make around end of life. Why, for example, don’t people clap when someone dies at hospice? Part of the reason is because the value system defining death does not include celebrating the end of life. Rather, our values foster fighting and holding on until the very end. Or why don’t we see providers as funny types of Gods that can “hasten a death but can’t make a life?” in the ED? Why, for example, when I asked the doctor to share a time when she delivered bad news, she didn’t say, “I had to tell a 18-year-old last night that her foot was broken and she’d be out for the soccer season?” In many ways, this would have produced a very different understanding of the ED, different from a story about telling someone they have a terminal disease. Or what would it have done when I
asked what made for a good day at hospice, a nurse told me, “the moment that we can do something different and not follow a routine procedure.”

Why, for example, don’t providers say how happy and relieved they are when someone who had been suffering dies? Why don’t providers share how frustrating and routine their days can be at the hospice or the ED and how difficult that becomes for their own relationships? And why, as patients, aren’t we generally curious about these professions, how they cope, and how they wind down at the end of the day? In many ways, these remain invisible and unsaid because the belief systems about death are not in place for these questions that expose words, actions, and behaviors to become thinkable or take priority, or even to be chosen next time when caring for a patient at the end of life. Indeed, the discourse of preserving life is powerful.
Chapter 10:  
Conclusions, Implications and Reflections  

This analysis provided a descriptive picture of the way death is handled inside an emergency department and hospice. Specifically, it illustrated the reoccurring ways providers deal with and resolve the messiness and chaotic nature of death. Furthermore, this analysis exposed the nature of talk at both places and described how providers’ own work practices become transformed to deal with the underlying tension surrounding death, to provide humanistic care in light of institutional norms, as well as allow them to survive against their own humanity. In doing so, this analysis illustrated how their care practices shape a particular orientation toward life and death. Further yet, this analysis provided a textured picture of how providers’ own talk and care practices enable and constrain their ability to make meaningful choices around the end of life. Essentially, what I described are the research questions that have guided and shaped this study from the outset.

Therefore, this chapter will do several things. First, I will tie together what was previously said in earlier chapters with my research questions and actual findings. Second, I will describe the contributions this study makes to current literature, current theoretical understandings as well as its practical contributions. Third, I will outline several questions this study further raises as well as the implications of this study. Finally, I will conclude by reflecting on the purposes and audiences of this study and suggestions for future research.
Competing Discourses of Care at the End of Life

This study examined discourse. Specifically, it explained how discourses influence and provide particular rhythms for understanding life and death. Even more, it described how competing discourses orient us to the world in a particular way and in so doing, put into play a way of feeling, thinking, and talking about death. Further, this study scrutinized how language organizes meaning and also naturalizes meaning around care, health, and death. Beyond organizing and naturalizing, however, this study illustrated how these discourses are decorated to be unique and different but are inherently chaotic, wild, and tension-filled thereby putting into play competing relationships around end of life. In short, discourses around end of life are in crisis.

I use the word crisis not to define that death is a problem or that our way of handling death is broken because as I mentioned in chapter one, to define death as a problem suggests there are answers and ways to fix it. This is not the case. Rather, by crisis I mean a crisis over meaning and a crisis over what to value at the end of life. The good thing is that a crisis can be a turning point in a sequence of events (Treichler, 1990). Healthcare reform in many ways bespeaks of a society trying to figure out what to value. And what to value is largely determined by meanings surrounding health. This study has not judged healthcare practices but looked at how dying patterns shed light on a larger system of meaning.

A crisis over meaning surrounding healthcare offers society and economies a turning point where the negotiation of meanings are contested even in subtle ways, questioning accepted practices and assumptions about dying. Again, the crisis is not about death, but about the meanings surrounding death. In chapter five, I described how
both the ED and the hospice are colonizing sites. What I mean by this is that each site has incredible power and access to produce, reinforce, and colonize a particular understanding of death and dying.

For example, colonizing meaning around death standardizes insurance rates and reimbursements on how death should be handled and where it should be handled. Further, providers must work and spend their time with patients. Even more, it standardizes what can be said around end of life and standardizes our access to recourses around end of life. And even more troubling, colonizing meaning standardizes specific smells, sounds, colors, and feelings around end of life. Clearly, our meanings and widely accepted practices and assumptions about death are colonizing and even more are in a constant flow in one direction. This kind of inertia is naturalizing certain behaviors and practices around death, even though they are also being disrupted.

Dying patterns are being disrupted on many levels including legislative battles, rising insurance costs, overcrowded waiting rooms, aging populations, increased chronic illnesses, battles of provider compensations, souring healthcare costs, provider shortage, and social media. Importantly, this study has illustrated that these disruptions are largely played out in language. This study also informs us that we know that these same disruptions are filled with tensions and contradictions. In the past 200 pages, we have together felt the unforgettable rhythm of both of these sites that are subtly calling into question some of our widely accepted practices and assumptions about dying. This same rhythm has disturbed our current understandings of much of health communication research.
Contributions to Health and Organizational Literature

This study moved beyond a mere description of the behaviors and practices in healthcare settings to illustrate the trenches of clinical life. More, this study took Hirschmann’s (2008) advice of going to the trenches and training grounds of clinical life to the trenches where lived experience unfolds. In doing so, this study helped underscore the importance of context, culture, and language to understand what is going on and explain why this is going on. Further, it extended Hirschmann’s call to develop evocative accounts that put pressure on health researchers today to develop more textured theories of communication and human interaction that respond to the changing field of medicine.

Further, I did not intentionally try to make this study messy or complex, but these sites are messy and complex. For that reason, I believe dwelling in the disorder of life and human interaction rather than trying to “clean up the mess,” allows us to experience a much more textured feeling of life in these environments. This textured feeling matters for health research because it conveys a feeling for what these places are really like, how they are experienced, and how providers manage their own self working in these places. Even more, this feeling has introduced you to a host of norms, realities, stories and experiences that are often rarely heard yet deeply misunderstood. After all, we learn best from and with others.

For that reason, this study respected the voices of others in generating knowledge with my decision to incorporate providers’ as well as my own experiences of these places. Although the ways I have incorporated these voices and quotes are somewhat subjective, there is tremendous value in paying attention to the people who work in these settings. After all, providing a more evocative account through the voices of others
around of end of life has allowed me to detail the tension-filled nature of these places.

My study moved beyond mere behavioral accounts of clinic life to the tensions and struggles of these sites. In doing so, this study has helped developed a richer understanding of interpersonal interaction to include the complexity and dynamics of these relationships that are being produced in a variety of competing ways. Providing accounts that better respond to our changing social situations, especially around death is useful for developing models of communication that are more responsive to the endless tensions and struggles over meaning. Further, this study provided a contextualized understanding that has revealed how death is not orderly, static, and coherent, but is fragmented, full of paradoxes, and ironies. After all, life is complicated, and so our understanding and theories of communication and interaction if we want to be able to respond and act meaningfully in a variety of settings.

Theoretical Contributions

I did little at the time when I was observing the ED and the hospice to directly reflect on the ways in which providers understood and framed the tensions inherent to their jobs. It was not until I had left the field that I began to see and feel how different people come to make sense of contradictory meanings in different ways. I experienced contradictory meanings surrounding death at both places, which I wrote about in chapter six.

Providers at the ED and hospice, on the other hand, have particular and reoccurring ways for dealing with and resolving the tension around providing humanistic care in environments organized by institutional norms. Embedded in their talk are stunning contradictions that slowly begin to surface through their routine practices. For
example, organizing providers’ experiences around tensions allowed me to see how they enjoyed sharing their experience about how meaningful work is to them. But in practice, these wishes and hopes often got suppressed in an effort to provide care in light of organizational routine practices that stripped away some of their best and most honest intentions for making a difference that made a difference in medical care. More, organizing providers’ experience around tensions helped this study move away from individuals’ behaviors to an understanding, and critique, of the social and organizational conditions under which individuals act in regard to medical care.

Even more, organizing their experiences around tensions exposed the complexities and contradictions of how a particular culture handles and constructs death. Exposing the complexities and contradictions of the way death is handled adds to our understanding of organizations and even more, to processes of organizing.

Specifically, this project exposed how the ED and the hospice organize in the first place and continue to stay organized through the transformation of care practices that ultimately worked to tame death. Even more, this study adds to theories of Discourse by describing what happens when Discourses like those that surround the ED and the hospice become organized and disrupted.

Earlier in this project I identified several ways discourses have been understood and at the time, I thought they were very useful ways of making sense of discourses. But what is missing is an understanding of what happens when discourses compete and even more, how discourses become coded and closed off from critical engagement. The additions to our understanding of discourse are useful because they illustrate how old and often standardized models of care cannot always represent the complexity and
extraordinary nature of human life. Further, understanding discourse as fleeting and competing allow for spaces to become visible where actual lived experience unfolds. These spaces detail how discourses become organized and unorganized thereby making visible meanings that have previously been suppressed and unquestioned.

Focusing on discourse and they ways they become organized exposed the juxtaposition of these places. Even more, processes of un-organizing help to see and feel the emotional, performative and unpredictable nature of this work. Further, this study and its attention to organizing features of talk did so from the ground and the floor, where actual lived experience unfolded. For that reason, this study is unique in its practical contributions.

Practical Contributions

From the outset, the ED and hospice have asserted that they are unique and that you can’t really understand what they are like until you are there. This focus on distinction allows both sites to claim uniqueness through their talk, care practices, behavior, stories and culture. In doing so, they try to distinguish themselves from other settings. But what is happening is that they are creating a uniqueness paradox claiming uniqueness that they are, in fact, not unique (Martin, Feldman, Hatch, Sitkin, 1983).

This study illustrated how both sites believe they are unique and distinct from other healthcare settings. But claiming to be unique creates more tension for providers. Most of the practices that are considered unique have become institutionalized, thereby making whatever was considered unique, routine. For example, in the hospice, one of the unique qualities is the hospitality cart that comes around every afternoon at 3pm offering patients and their visitors a beverage and snack. Patients and families frequently ask
when the hospitality cart will arrive. They wait for it and many patients even structure
their afternoon around the unique hospitality cart because they felt like they were at home
having a choice over what to drink and eat. But the unique hospitality cart became
inherently standardized, routine and organized. The hospitality cart lost its uniqueness as
a consequence of becoming an institutionalized practice. Even more, it created a tension
around patients desiring the cart every day at 3:00pm but also a disdain for something not
routine in an environment built around so many routines and protocols. Consequently,
what was once unique became routine and now cannot not be routine for in doing so, will
lose what was once perceived to be unique.

Understanding the uniqueness paradox helps us see further that practices of
handling death are not unique either. More, it has helped underscore that death is not a
uniform event whose meanings are universal and accessible to everyone, but it is an event
that wants to be unique and different from something else. Further, uniqueness sets up
boundaries around understanding individuals and the work they do.

Uniqueness helps providers organize their experience. “We are different from a
hospital setting and won’t try to keep you alive on unnecessary machines.” Or, we won’t
stop caring for you like they stop doing at hospice.” The uniqueness paradox has a way of
mystifying all things. Specifically, the uniqueness paradox in many ways often prevents
us not to ask questions when someone tells us they work at hospice or the ED. Often
times, we do something similar, our voice changes, and it’s serious stuff when we hear
someone works at the ED or hospice. “Ohhhh, I can’t imagine,” becomes a consistent
response that unfortunately closes communication and prevents a discussion from taking
place. But this is the very moment we need to start talking in an effort to understand the
world as they experience it in the name of caring and healing of our many ailments. This study has shown how much they enjoy talking about their work. They are people who also need to be cared for and listened to as our healthcare system seeks reformation.

Limitations and Future Directions

This study, like all studies, has limitations. Specifically, I chose to work through the challenges of representation by using alternative forms of writing such as autoethnography and narrative styles. This decision, in part, allowed me to escape the constraints of traditional writing as well as lessen the dangers of speaking for others in sites that constantly cut to the core of who I am. I realize, however, that in taking this decision to incorporate more alternative forms of writing I might potentially make the reader feel uncomfortable who may be more sensitive to these types of writing or take these pages as less serious or mere “play.” The goal is just the opposite. Further, I am also aware that like any form of writing, choosing a new form of expression can simultaneously inhibit other forms.

Another limitation of this study is that in trying to provide a descriptive and honest account of the messiness of healthcare, this analysis is not theoretically rich or rigorous. Further, this study does a better job of raising questions rather than answering questions from a theoretical perspective. Another limitation of the study is the enormous ethical commitments it has demanded of me. As a result, I got caught between staying and leaving these settings and I left them both feeling exhausted, frustrated and vulnerable. This in turn, made me take a break from this study to literally heal before writing the report. Finally, the other limitations of this study I will address by way of outlining future directions for what we need to study next.
First, I think a substantive understanding of the ED and the hospice can be incorporated into actual medical training and teaching so that providers may begin talking about the real difficulty of this work. If instructors so desired, we may begin to incorporate systems and practices that help to heal the healers and their own personal relationships and struggles. Even more, future research into medical education should explore how a more fragmented understanding of clinical life can generate better models of communication and decision making that can respond to the changing healthcare environment. Second, future research should explore the role and consequences of culture for dealing with end of life issues, beyond U.S. borders.

Third, future research in end of life discourse should examine the role of emotional labor and burnout. If I were to continue with this project, I would carefully focus on how discourses expose the consequences of emotional labor and potential burn out for making meaningful choices around the end of life. Fourth, future research should incorporate the importance of palliative care. Although I used the term sparingly in this study, I used the idea several times. Future research should expand understandings of palliative care beyond a distinct form of care delivered by a special team during difficult moments in life and death. Palliate literally means to make better. Therefore, every one of the providers on these pages endlessly palliated others, just under different guises. That said, I encourage this research area to explore how providers palliate others and each other and how more providers can do so instead of isolating it as a “specialty” or “emphasis” in medical care and medical education.

Finally, future research should seek to expand our thinking of identity and identification in light of more stigmatized work with institutions that often act like “total
institutions” and where work always stays with you, even when providers leave the ED and the hospice to go home (Goffman, 1959; Goffman, 1963; Tompkins & Cheney, 1983). The future research agenda is large and so, too, should be our motivation for exploring the intersections of organizational and health communication.

Moreover, I would encourage scholars to continue offering new insights regarding the storied nature of organizational and clinical life. Both organizational and clinical life is communicated and narrated through stories, because stories are essential and central to communicating about and organizing health (Harter et al., 2005). Paying greater attention to these stories not only offers frameworks for interpreting how health is constituted, but also takes us beyond the realm of the biomedical to the realms of the human dimensions of individual health and healing. Further, “stories can heal and they can offer new ways of imagining how the interstices of the mind, body, and spirit ruptures our ontological and epistemological foundations and creates new openings” (Zoller & Dutta, 2008, p. 462). In short, we can augment dominant ways of knowing through stories and our other senses.

Stories, however, were not my only access to understanding these places. What mattered most was being there on the floor to feel lived experience unfold and to be part of these interactions. For these were the moments I understood the most. Together, I hope theses stories, voices, and experiences have colored an important picture into the intricate rhythms of these places that are organizing meanings about death as well as helping to re-organize the challenges and opportunities of coordinating care around the end of life.
Closing

The ED and hospice communicate comfort and discomfort. They embrace courage in the name of fear. They are filled with compassion. They are full of incredible knowledge. They are places that surprise, disappoint and scare me. They make me feel free and imprisoned. They are places people come to for help and hope. And they provide immediate and prolonged answers to those who come close. But above all, they are places that beat, bleed, and breathe meanings surrounding the sacredness and fragility of life and death into all those who come near. Through my own engagement, these places have essentially provided their own rhythm for understanding care at the end of life that is part artistic and part improvisation.

In closing, I made no promises in this dissertation to improve care for the dying. Instead, I promised to become part of the interaction in both of these sites in order to provide an interesting, evocative and compelling research report. If this dissertation has challenged your understanding of clinical life to be something other than “normal,” and “non-messy,” I am happy. And if these narratives that have been slivered into this project in much the same way that they have slivered into my heart and train of thought as I write, have someone slivered a piece of your heart, my goals have been met.

For if nothing else, my hope is for you, the patient, to contemplate the accounts and stories from providers at both sites to understand them and their own experiences, fears, frustrations, demands, expectations, and energies they intricately balance when you are in their presence next.

My hope is for you, the provider, to gain a better understanding and appreciation for the tight rope you all endlessly walk when caring for others. And in listening to other
providers, I hope you have questioned some of your very own practices as well as wonder what it would look like, feel like, and sound like to start doing things a little differently in your practice.

And my hope for you, the academic, is to have become a little more willing to lay yourself bare when you write, think, feel and inquire. For if nothing else, I hope you are motivated to underscore how our very own discourses can be oppressive, confusing and closed for many who do not speak this language. Further, I challenge you to “let yourself go” a little so as to have your voice and work be more accessible to audiences other than your own, and to be vulnerable to some of the challenges and failures of our work so that others may learn from them, and with you.

Finally, my hope for us all is to listen to the voices on these pages with respect, humbleness, compassion and courage. Even more, I hope these pages have generated small and large discussions where none seemed needed before. We are at a crisis surrounding the meanings of healthcare in general and death in particular. This study is one suggestion into this crisis over meaning and what to value. Further, in this analysis I have proposed a more complex and textured understanding of how death is handled, understood and experienced by people working around it every day. This kind of understanding is essential to reform our practices around death and dying if we are to make it more meaningful for everyone.
References


National Hospice and Palliative Care Organization, Retrieved on May, 2009: http://www.nhpco.org


Wall Street Journal, 2/26/2008 (medicare spending)


