



University of
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Amherst

Respirators, Morphine and Trocars: Cultures of Death and Dying in Medical Institutions, Hospices and Funeral Work

Item Type	dissertation
Authors	Fox, John Martin
DOI	10.7275/1663918
Download date	2024-11-26 19:11:54
Link to Item	https://hdl.handle.net/20.500.14394/38695

RESPIRATORS, MORPHINE, AND TROCARS:
CULTURES OF DEATH AND DYING IN MEDICAL INSTITUTIONS, HOSPICES
AND FUNERAL WORK

A Dissertation Presented

By

John Martin Fox

Submitted to the Graduate School of the
University of Massachusetts Amherst in the partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

September 2010

Department of Sociology

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John Martin Fox

Approved as to style and content by:

Robert Zussman, Chair

Donald Joralemon, Member

Gerald M. Platt, Member

Elizabeth Wheatley, Member

Donald Tomaskovic-Devey, Department Chair
Department of Sociology

DEDICATION

To the memory of my mom and dad, Jean and Gene.

ACKNOWLEDGEMENTS

I could not have finished this dissertation without support from many sources. My dissertation committee deserves special thanks. Libby Wheatley helped me with the transition from undergraduate to graduate school and served on my various committees at UMass. Don Joralemon came through as my outside member when many others could not and provided strong support. Jerry Platt saved my career at one point, encouraging me to go forward at a time I wanted to quit. My committee chair Robert Zussman, meticulously and patiently, guided my transition from a knowledge consumer to a knowledge producer. I hope I have done you proud.

Many people participated in this project. My sincere gratitude goes to all of those who allowed me to observe you or granted me an interview. A special thanks to three people (who must remain anonymous) who served as my co-principle investigators for the purpose of gaining approval from institutional review boards. I am most grateful to those dying patients and grieving families who allowed me to observe them. I am honored that you allowed me to be so close during these difficult and intimate times.

My friends and family have endured my frustrations, celebrated my joys, and at least feigned an interest in death and dying. To all of them I am deeply grateful. My partner in life, Kim Chilvers, bore the brunt of my frustrations more than anyone and provided emotional and intellectual support in ways only she can do, even when I was not receptive. This work is your accomplishment too.

ABSTRACT

RESPIRATORS, MORPHINE AND TROCARS: CULTURES OF DEATH AND DYING IN MEDICAL INSTITUTIONS, HOSPICES AND FUNERAL WORK

SEPTEMBER 2010

JOHN FOX, B.A., UNIVERSITY OF CALIFORNIA, SANTA CRUZ

Ph.D., UNIVERSITY OF MASSACHUSETTS AMHERST

Directed by: Professor Robert Zussman

In this dissertation I explore the cultures of death and dying in medical institutions, hospices and funeral work. I argue that not only are there competing cultures of death and dying in American society, but within these institutions that produce tension and conflict, sometimes among the workers, other times between the workers and those they serve, and other times between the institution and outside organizations. Medical institutions, by medicalizing death and dying, constructed a “death as enemy” orientation in which doctors fight death with the use of medical technology, practice detached concern from their patients, and marginalize religion and spirituality. On the other hand, a “suffering as enemy” orientation has also emerged, primarily in the form of palliative medicine, in which needless suffering is considered worse than death, therefore life-saving technology is removed, doctors empathize with patients and families, and spirituality is incorporated. Hospice started as a social movement to change how dying patients were treated at the end of life, addressing patients’ physical, spiritual and emotional pain. However, the bureaucratization of hospice, particularly the Medicare

Hospice Benefit, has led to a compromise of the social movement's ideals and these competing orientations shape how hospice workers, particularly nurses and social workers, express frustrations with their work. Funeral directors assert their jurisdictional claims of the right to handle the corpse and assuage the grief of the bereaved, through embalming, informal grief counseling and the funeral performance, but funeral directors encounter resistance from large funeral corporations and the funeral societies. Large corporations centralize embalming, turning the corpse from a craft to a product, recruit other professionals to practice grief counseling, and sell standardized funeral packages. Funeral societies challenge the necessity of embalming and funeral directors' expertise in grief counseling, and focusing on the value of simple, dignified and affordable funerals. I conclude this dissertation by showing how orientations toward death and dying vary in American society and these institutions because of tension between experts who espouse a particular orientation and challenges from within and outside these institutions.

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CHAPTER 1

CULTURES OF DEATH AND DYING IN SOCIAL INSTITUTIONS

Introduction

The scene is familiar from television shows such as *ER* and *Grey's Anatomy*. Paramedics rush a patient into the emergency room or a nurse in an intensive care unit shouts "code blue." Crash carts are deployed and a doctor orders a procedure "stat," such as "start a central line." The doctor might intubate or "bag" the patient or, more dramatically, "shocks" them by applying the paddles to the chest immediately after someone yells "clear." A nurse yells something about "V-Fib" so the doctor orders Lidocaine and hollers, "charge to 300! Clear!" and shocks the patient again. Sometimes the patient's heart starts again, and because of the miracle of medical technology the patient's lives, although for how much longer we rarely find out. Sometimes the efforts of the medical staff are in vain, and the doctor "calls it." Occasionally, the doctor does not quit until the futility of the exercise is apparent, sometimes pointed out by a nurse or another doctor. "Time of death, 2:25." A nurse or technician turns off the monitors, and the high-pitched continuous tone, which had previously been a series of rapid beeps, goes silent. The doctors and nurses leave the room and the last camera shot is the corpse on a gurney, with tubes penetrating the body and the floor littered with medical waste.

Much less familiar, but no less dramatic, are hospice deaths. In the movie *Magnolia*, Earl Partridge, played by Jason Robards, is dying at home under the care of a hospice nurse, Phil, played by Philip Seymour Hoffman. Earl regrets his adultery, failure to come to his ex-wife's deathbed, and estrangement from his son, Frank T.J. Mackey, a

misogynist, somewhat famous self-help author and seminar leader. After Phil tracks down Frank at Earl's request, Frank, extremely reluctant, visits his dying father. Although Earl appears barely conscious Frank begins his tirade: "You prick." Frank recalls how his mother died in pain awaiting a call from Earl, and as his bitterness overcomes him Frank says through his quiet rage, "I'm not going to cry for you... I want you to know that I hate your fucking guts... And I hope it hurts, I hope it fucking hurts." But Frank, who has cultivated a self-image contemptuous of unmasculine behaviors, breaks down crying: "don't go away, you fucking asshole, don't go away, you fucking asshole," as Phil witnesses the interaction. The last scene showing Earl and Frank's interaction is Earl awakening, looking up at Frank and opening his mouth as if he wants to say something, while Frank, who has stopped crying, holds his gaze at his father, anticipating his father's words. The scene ends there so we don't know what, if anything, was said, but we see the next morning that Frank had spent the night on the couch after his father died, and in the morning received news that Earl's wife, who was also estranged from Frank, is in the hospital and Frank goes to visit her. We are left with the suggestion that this family, once estranged, has come back together and begun a process of reconciliation, a process aided and witnessed by the hospice nurse Phil, who also breaks down crying the next morning after his duties are finished.

More familiar than hospices (but still less familiar than hospital dramas) are scenes related to funeral work. The Home Box Office series *Six Feet Under* is filled with scenes of grieving family members making funeral arrangements with the brothers who own the funeral home, David and Nathan Fisher. Typically, as the grieving families discuss their loved one the brothers show compassion and caring, speaking in a soft voice

and expressing condolences. Funerals on the show are opportunities for the bereaved to pay tribute to the deceased, often open-casket with the deceased dressed in their best clothes and appearing to sleep peacefully. The dirtier funeral work in the preparation room concerns the embalming, dressing, and making up the corpse, which is often done by either by David or Federico, a very talented embalmer. These scenes, however, focus more on making up the corpse to be presentable rather than the work with blood and guts inherent in embalming. While there is some veiled portrayal of arterial embalming, the dirtiest work, cavity embalming, is not shown. The embalmed and made-up corpse is ready for the funeral performance, which allows the bereaved to say goodbye.

Television and the movies are, of course fiction. While reality encompasses much more, television and the movies reflect aspects of the realities of death and dying. In my observations of medical institutions, hospices and funeral homes as well as my interviews with people who work within or against these institutions, I found that these scenes contain elements of truth. Though not as dramatically as in popular culture, doctors employ technology to save lives, hospice workers address the social needs of the dying patient, and funeral directors work to assuage the grief of bereaved family members. However, I found other practices, existing simultaneously and with some tension and conflict with the practices shown above. In medical institutions, sometimes physicians do *not* fight death with all available technological tools, but allow for the patient to die “in peace.” In addition, the decision to withhold treatment does not always come from the patient but from the doctor, and doctors sometimes work to convince patients and family members that death is preferable to employing life-saving technology that would likely cause suffering. In hospice, the bureaucratization of hospice in the United States includes

the Medicare Hospice Benefit, which includes rules by which a patient is to be recertified and eligible for hospice care; patients must continue to show signs of decline in order to continue to be eligible for hospice care, and those who do not meet the guidelines are often disqualified from hospice care. Many people understand that funeral directors handle corpses and have some understanding of embalming, but they do not know the details of cavity embalming, such as “aspirating,” or suctioning blood and other fluid from the internal organs and injecting embalming fluid, finishing by plugging orifices to prevent leaking. The work of the funeral director is dirtier and even more stigmatizing than what is shown on *Six Feet Under*. Taken as a whole, the fictionalized accounts of death and dying do get one point fundamentally right: there is not a single culture of death and dying in the United States, but multiple cultures, both across institutions and within them.

In this dissertation I explore the cultures of death and dying in medical institutions, hospices and funeral organizations. I argue that there are competing cultures within these institutions that produce tension and conflict, sometimes among the workers, other times between the workers and those they serve, and other times between the institution and outside organizations. For example, a patient and their family might embrace the idea of employing technology in the fight against death, but when a doctor believes that fight is futile they often have trouble convincing the family not to fight. Another family might accept the inevitability of death and enroll in hospice care so the patient can experience a “good death,” only to find that because the patient does not show enough signs of decline, the hospice discontinues care and the patient is left to die without hospice services. A family which has lost their beloved might trust the

professional judgment of the funeral director and consent to embalming, dressing, casketing, grief counseling and the funeral, but they might want to be spared the details of what embalming entails. Furthermore, the family might never know if the funeral home is owned by a large corporation that controls the work of the funeral director, so their loved one might not be in the direct care of a funeral director or his or her employees but are embalmed in a centralized location outside the funeral home by employees of the corporation. In addition, the family might not know about consumer organizations, such as funeral societies, that counter the funeral industry's claims regarding the positive emotional effects of embalming on the bereaved; embalming, the funeral societies argue, is one of the main avenues by which funeral directors financially exploit the bereaved.

There is a knowledge gap between the experts working in these institutions and those they serve, which has widened in modern times. As Philippe Aries argues in his classic historical study *The Hour of Our Death*, “[T]he death of each person was a public event that moved, literally and figuratively, society as a whole. It was not only an individual who was disappearing, but society itself that had been wounded and that had to be healed” (559). With modernization came the hiding of death within institutions; the dying were shuttered into medical institutions and the dead were tended to by the funeral industry. Over time, expert knowledge of dying and death increased but lay knowledge did not keep pace. This knowledge gap is the result of not only acquiring expert knowledge but what the experts promoted, and they did not promote, to the public. Doctors wanted the public to embrace life-saving technology, hospice workers wanted the public to support a social movement to change the medicalization of death and dying,

and the funeral industry wanted the public to accept embalming as good for the grieving process. The limits on medical technology, the limitations imposed by the Medicare Hospice Benefit, and the dirty work of embalming are hidden and elusive, thus leading to an increased knowledge gap.

Sometimes the sources of conflict are within the institutions, other times from outside. The conflicts arising from the understanding of different cultures affect how doctors, hospice workers and funeral directors see their work. Doctors' fight against death, hospice workers' pursuit of a good death and funeral directors assuaging grief are cultures of death and dying that sound familiar. Doctors not fighting death, hospices dropping patients for not dying fast enough, and funeral directors' ability to assuage grief being challenged by consumer societies and corporations do not sound as familiar. These less familiar orientations are side-by-side with the ones we see in popular culture. When people who are embracing different cultures meet, that is, to employ a cliché, when the trouble starts.

Cultures and Institutions of Death and Dying

Culture is a vast area of study within sociology and other social sciences. For this dissertation I see culture as a "tool kit" (Swidler 1986:273) that people employ to address life's problems. Culture is, therefore, not so much a unified set of norms, beliefs and values that motivate action but a resource of symbols, rituals, stories, and world-views. Within social institutions, culture is transmitted in everyday, face-to-face interactions (Fine and Kleinman 1979; Kleinman 1988). Local cultural orientations, the tool kit emerging out of interaction within these institutions, are varied, in-flux, and in many

cases, at odds with one another. Institutional actors, then, choose from a variety of cultural tools to address institutional goals (Scott 1991). The ideal is that the appropriate tools are chosen for the appropriate goals. Disagreement over when, how much or whether respirators, morphine or trocars¹ are used are often indicators of disagreement over the goals. However, institutional actors do not always pick and choose from a vast assortment of tools, but the tools, both material and nonmaterial, shape what practitioners actually do. For example, hospice nurses' work is, to a large extent, shaped by the bureaucratic culture in which they work. If they had a choice, they would not choose criteria or the process required of them by the Medicare Hospice Benefit, but it is the tool by which hospices can afford to do their work so hospice nurses yield to the demands.

Medical institutions, for example, are set up to fight death. Medical settings were among the first sites in which death became denied, medicalized and hidden away from the public eye in hospitals (Aries 1981). As physicians accumulated the material tools to fight death, death came to be seen as a failure, both of physicians and the medical field in general (Moller 1996; Comaroff 1984; Parsons, Fox, Lidz 1973). The tools wielded in the fight against death include life-saving technology, such as organ transplants, respirators, defibrillators, CPR, dialysis, and heart catheters. In the most literal sense, medical technology is awesome. It evokes awe. In order to wield such technology physicians must also limit the impediments to the fight against death. Their own feelings might get in the way, so they learn how to detach themselves from their patients (Lief and Fox 1964), and marginalize religion and spirituality, including chaplains and clergy who might be

¹ A trocar is an instrument used in cavity embalming and will be discussed in Chapter 7.

accommodating of death. In these ways, medicine generates what might be thought of as a culture in which death is the enemy.

But medicine's tools are not limited to those that fight death. These other tools are not so material as defibrillators or organ transplants. Rather, they are a set of ideas that sees suffering, not death, as the enemy. Palliative medicine is at the forefront of the suffering-as-enemy culture, though I found it in the unlikely setting of the intensive care unit as well. The idea of suffering-as-enemy draws on pharmacological technology to manage pain, but otherwise promotes discontinuing life-saving treatment so patients can die in peace. If some doctors are taught to detach themselves from patients, others draw on various religious and spiritual sources to affirm their own and their colleagues' emotional connections. Although frequently ignored in high tech medical settings, clergy and chaplains are a part of palliative care teams. They not only recognize but promote an understanding of the phenomena of spiritual suffering. Within palliative medicine, clergy and chaplains do not promote a redemptive value of suffering but work to alleviate spiritual suffering.

The social movement that helped create hospice also provides tools for thinking of suffering as the enemy. Dame Cicely Saunders' vision of how patients should be treated at the end of life has been, to some extent, realized. Instead of dying in a hospital alone, afraid, in-pain, and without finding meaning in life, many patients are having better deaths, with less pain, more emotional comfort, and a focus on spirituality. The hospice social movement is concerned with providing patients with "good" deaths, similar to the interactions between Earl, Frank and Phil in *Magnolia*. Hospices work to alleviate physical pain and other symptoms, offer spiritual support to patients and family

members, help the dying address “unfinished business” with loved ones, explore issues surrounding the afterlife, and tend to patients and family members emotional needs. In order to remain a viable option for dying patients, hospice had to become institutionalized. The Medicare Hospice Benefit led to a bureaucratized culture of hospice, which in turn led to a compromise of the social movement culture. Hospice not only includes a set of ideas that were meant to free dying patients from the restrictions of medical institutions but also a set of ideas that restrict access to hospice care, imposing its own restrictions on the dying. Hospice, then, generates both sensitivity and caring toward dying patients and a bureaucratized institution, characterized by regulations that are neither sensitive nor caring. These competing sets of cultures—the hospice social movement and bureaucratized hospices—exist simultaneously. Hospice workers draw on both and the ways they do so in turn shapes how they see their work. Hospice workers who see themselves as part of a social movement tend to blame the rules when patients no longer qualify for care under the Medicare Hospice Benefit. On the other hand, hospice workers who identify as health care workers embrace the rules and regulations and are quicker to blame uncooperative patients rather than the rules.

Of the three institutions, perhaps the least amount of tension is within the funeral industry. The professional culture of the funeral industry claims two jurisdictions: handling the body and expertise in assuaging grief. Because removing, embalming, dressing, and grooming the corpse is such stigmatizing work, professional funeral directors promote their expertise in assuaging grief in order to manage stigma. By displaying the corpse as if it were “resting in peace,” engaging in informal grief counseling and directing the funeral performance, the professional culture of funeral

directors claim expertise in assuaging grief. However, even the funeral industry is not free to tension. In particular, funeral directors draw on three very different set of tools—one from a professional world, a second from business, and a third from consumer regulation—each of which is suited to a different set of tasks. Much of the tension challenging the professional culture comes from the business culture, which exists in some degree within all for-profit funeral homes but most strongly within corporate conglomerates such as Service Corporation International (SCI), which buys independent funeral homes in particular areas to create “clusters.” In the business culture, the pursuit of profit is the driving force, and many practices at corporate funeral homes are intended to maximize profit. For example, at many SCI-owned funeral homes the embalming is not done by a funeral director or an embalmer working under their supervision, but at a centralized location by an embalmer who does not know the deceased or their family, turning the embalmed body to a product rather than a craft. Furthermore, grief counseling is not done by the funeral director but sold by the corporation, who employs professional grief counselors the bereaved may access through a central phone number. The funeral performance can be somewhat tailored to fit individual needs, but much of their product is packaged and the bereaved can choose from several options. Another source of resistance to the professional culture of funeral directors is the consumer rights culture, represented by funeral societies and their most famous muckraker, Jessica Mitford. The consumer rights culture attempts to discredit funeral directors’ claims of embalming as therapeutic and accuse funeral directors of exploiting families financially. While the business culture and consumer rights culture have little in common, they are both aiming to reduce funeral directors’ professional jurisdictional claim in assuaging grief, which, if

successful, would reduce funeral directors to their most stigmatized jurisdictional claim: handling the body.

The various tools that practitioners deploy in the ways they think about and treat death have various sources. First are institutions of “expertise.” The driving force of expertise is the application of specialized knowledge in the service of others, so it is, or at least claims to be, working in the interests of patients, families and clients. Expertise provides doctors, hospice workers and funeral directors the know how to save lives, alleviate suffering, or assuage grief while those they serve know little about these challenges; therefore, the degree in which patients and clients have choices in these matters is shaped by the knowledge the experts share with them. Second, there are “activist” movements, including the hospice movement and the consumer rights movement in funeral work. These activist movements typically work in the interests of patients, families and clients by increasing knowledge, thus providing more choices and autonomy. Activist movements take contrary positions to the experts, though whether the activism is working within the institution to reform it, setting up a separate institution or changing the institution through legislation and regulations depends on the institutional context and relationships. Bureaucratized rules and regulations, exemplified by the bureaucratized culture of hospice and, to a certain extent, the consumer rights culture of funeral work, provide the third set of tools. The driving force of rules and regulations is the rational and efficient operations and practices. Bureaucratic rules tend to constrain individual choice for the sake of a smooth-running institution. However, not all institutional actors draw equally on bureaucratic logics. Hospice nurses and social workers, as well as funeral directors, both face and seem to take more seriously rules and

regulations than do physicians and hospice chaplains. Finally, economic constraints—and those who administer them—encourage minimizing costs, raising funds, and maximizing profits. While these constraints appear everywhere I looked, they are most central within the for-profit funeral industry, especially within corporations. The more important profit is to the institution, the more knowledge is hidden from clients so that their customers would choose their services over another; in other words, it is in the interest of institutions embracing an economic culture to keep clients ignorant, for if they are ignorant they cannot make alternative choices. While medical institutions, hospices and funeral work have, to some extent, all four cultural sources (professional, activist, bureaucratic and economic), the way they play out in each organization is, of course, very different.

Why This Matters

Imagine, if you will, you come home one day and find your loved one unconscious and not responsive. You do not know what is wrong, but you know that if you have any hope in saving your loved one's life you had better call 911. The ambulance arrives and the emergency medical technicians start applying CPR. They rush your loved one to the hospital, and in the emergency room doctors are able to keep your loved one alive but they are in critical condition. They are moved to the intensive care unit, where doctors determine, after your loved one has already been intubated and hooked up to all sorts of life-saving devices, that any sort of heroic measures would be futile, constitute violence upon your loved one, and you should call the family together to say goodbye and allow your loved one to die in peace. However, you are not ready for this. Because you want to do everything to save your loved one's life you might fight for

their life until there is absolutely no chance. The doctors will not tell you that there is absolutely no chance of survival because statistically it is probably not true; instead, they will say things like “a very slim chance,” but all that does is give you hope for survival. Most important, doctors are supposed to fight death, right? In this situation you are getting a crash course how a concept of suffering-as-enemy culture trumps a concept of death-as-enemy—at a time when you are least able to learn it.

Or maybe you agree with the idea that suffering is the enemy, but instead of an acute ailment, your loved one has been fighting a chronic disease such as cancer. Your loved one is getting worse, to the point in which the disease is now “terminal” so a doctor diagnoses your loved one as having less than six months to live and refers your loved one to hospice care. You sign up and it is fantastic. You can go to work, because volunteers will come to sit with your loved one while you work. Your loved one is getting opioids to control pain along with a bowel regimen to control constipation. You and your loved one are getting emotional support from the social worker, volunteers, chaplain and even the nurses. This time provides an opportunity for you and your loved one, as well as the rest of the family, to work through unfinished business, apologize and forgive, and prepare to say goodbye. These services are so good that your loved one is in much better spirits. When it is time to recertify after 90 days of being on hospice care, the nurse determines that the disease has not progressed, which means your loved one cannot be recertified and you no longer qualify for hospice. You might have thought, from reading the works of people like Cicely Saunders, that hospice will be there until your loved one dies. The Medicare Hospice Benefit, though, has other requirements. Abandoned by hospice, your loved one dies just days after being dropped from hospice care. You are getting a crash

course in how bureaucracy trumps the social movement values of hospice—and again at a time when you are least able to learn it.

Or your loved one has died. It is now your responsibility to make funeral arrangements. You have many decisions to make. What funeral home will you choose? Perhaps you'll choose a local "mom and pop" home in your community because you went to a co-worker's funeral there a couple years ago and it seemed like a nice place. But they may have been taken over by a corporation since you were last there, though you would never know it because the old mom and pop name, "Joseph Smith and Sons," remained the same. You go in to make arrangements and the funeral arranger hands you a price list for services. It seems expensive, but how would you know, since you haven't shopped around for the best prices? You look at the caskets in the display room, since your loved expressed a preference to be buried and you want to honor that wish. There are all sorts of caskets, ranging from a cardboard box to fancy velvet-lined 32 oz copper casket, so maybe you settle halfway and purchase an 18-gauge steel casket with crepe interior. What about embalming? Do you want to see you loved one laid out as if resting in peace so your last memory is not seeing them in the hospital hooked up to machines? Will it be good for you to see them and say goodbye, or would it be traumatic? What kind of service do you want? Could the funeral home accommodate the kind of service you want? Where do you go if you need to talk to someone in the coming days or weeks or months? Later, after you have paid, you find out that you could have done the same service for a much lower price. Again, you are getting a crash course on the abilities and limits of the funeral industry—and once more at the time when you are least able to learn it.

These crash courses are hypothetical but they are also real. They come about because the institutionalization of death and dying has led to a wider knowledge gap between the experts in death and dying and those who are not. This knowledge gap not only shapes the experiences of those who work in these institutions but shapes our experience when we come into contact with them. Many people know that medicine treats death as an enemy, or about the hospice social movement, and the professionalism of the funeral industry. But many of us do not know that there are those within medicine who see suffer as the enemy, that there are bureaucratic constraints in hospice, or that both corporate concerns and consumer rights pertain to funeral work. On the individual level, I hope my dissertation leads to a narrowing of the knowledge gap and can facilitate lead to some kind of education about these institutions before we have to engage with them so more people can avoid the crash course.

This knowledge gap not only has consequences on the individual, but political consequences. I am not going to spend a lot of space on this topic, but several things happened in the political arena in the course of my data gathering that deserves a comment. Death and dying have become politicized, partly because of a lack of knowledge among the public. The Florida and U.S. federal governments' involvement in the Terri Schiavo case, in which a woman spent 15 years in a persistent vegetative state before her husband successfully petitioned to have her feeding tubes removed, was politically motivated. For example, the legal counsel to Florida Republican senator Mel Martinez, Brian H. Darling, wrote a memo that was distributed to republican congress members, saying that "This is an important moral issue and the pro-life base will be excited that the Senate is debating this important issue" (Allen 2005). More recently, the

current debate on health care reform includes a discussion on end-of-life care that is characterized by former Alaska governor and vice-presidential candidate Sarah Palin as “death panels” (Barr 2009). These claims would not resonate with an educated public that understood end-of-life care issues. I hope that readers consider the political consequences of this knowledge gap between those who work in the institutions and those they serve.

Motivations and Interests

I am promoting the idea of a narrow knowledge gap in the pursuit of more, or better, choices for the dying and bereaved. Personal experiences have shaped my motivations and interests, including the death of my parents, my experiences being an activist, and more recently becoming a sociologist. When I was an undergraduate at UC Santa Cruz, I attended small forum discussing what one can do with a sociology degree and what one can study. A graduate student at the forum suggested choosing a topic to study that “pisses you off.” It was at that point I decided to study death and dying because I was unhappy with how government and institutions control the death and dying experiences of individuals and family members. After dabbling in the topic of physician-assisted suicide (a hot topic at that time), I started graduate school knowing I wanted to study death and dying. As I was sympathetic to activists, I became a hospice volunteer and thus began my data collection.

Over the course of data collection in other institutions, I began to see professionals who were motivated as I was—to make a positive impact on the death and dying experiences for individuals and families. Thus I began to have more of an appreciation for the professional who work with death and dying—especially physicians

and independent funeral directors. Not only did I gain an appreciation, but I identified with the experts because in a certain sense I imagined myself as becoming an expert, though one of a different sort. As I am motivated to use my sociological tools and skills to make a positive impact on death and dying, so are the doctors and independent funeral directors I studied. The relationship between activists and experts is one of strong ambivalence; on the one hand, activists loathe the power experts have, but on the other hand activists need experts to do their work, especially in funeral work. I return to this topic later in the dissertation.

As much as I embrace the activist and expert orientations I do not embrace the bureaucratic and business orientations because I see them as impediments to improving death and dying. I see the necessity of bureaucracy and how, ultimately, the Medicare Hospice Benefit has led to more good than harm, since more people can receive hospice services. While I sympathize with activists in the funeral societies to a certain extent, I think many of them have over-generalized the funeral industry and we all have a right to make a living. Some funeral society activists agree with me that some funeral directors are motivated to help people, but I think we disagree on how much profit drives professional funeral directors' work. Jessica Mitford seems to cast them an eye of contempt as "merchants of a rather grubby order," but I don't think it's that simple. Where we agree is our criticisms of the corporate funeral homes. I do not see how the corporations, in any sense, put bereaved families before profit.

There is no such thing as unbiased social research. The important point is whether I am fair in my analysis. I'd like to think that I am, but judge for yourself.

Organization of the Dissertation

This dissertation has nine chapters. After this introduction is the methods section, in which I expand on my process of discovery. Then I start the tour of the organizations in the substantive chapters, which are structured in a similar way. In the first chapters of each institution I set a foundation, generally reviewing the previous research and affirming that I have found what previous research has also found, so in the first chapters I use the data to illustrate previous research. In the second chapters I attempt to rock the foundations, analyzing the cultural tensions within each institution by using my data to cover the various ways in which death and dying is addressed. In other words, in the first chapters the data mostly illustrates the previous research, while the second chapters cover the distribution of events that show the various meanings of death and dying.

For example, Chapter Three discusses the medicalization of death and dying. Here, I argue that the medicalization of dying led to a death-as-enemy orientation, and that culture is characterized by the technological imperative, detached concern, and the marginalization of religion and spirituality. In Chapter Four I discuss the concept of suffering-as-enemy, in which technology is withdrawn, doctors sympathize with the plight of their patients in order to reduce suffering, and religion and spirituality are included in order to reduce spiritual suffering. This means that dying is still medicalized because it is defined as a medical problem; the goal of care, however, has changed from curing disease to alleviating suffering. The challenge for physicians is to convince patients and family members that the pursuit of a cure would be futile and would constitute “torture.” Sometimes, patients and family members have difficulty making a cognitive and emotional switch from death-as-enemy to suffering-as-enemy.

As for hospice, Chapter Five is a “celebration of hospice,” in which I analyze the social movement culture of hospice that also addresses suffering. After I review Cicely Saunders’ vision, lay out how hospice addresses the physical, emotional and spiritual needs of patients and argue that hospice, to some extent, is a successful social movement. However, in Chapter Six I examine the institutionalization of hospice. In order for hospice to succeed it had to compromise some of its ideals through the Medicare Hospice Benefit. Because of the Medicare Hospice Benefit, there is a bureaucratized culture within hospices, more so among nurses and social workers than chaplains, volunteers, and bereavement specialists. My contribution is that these rules shape the emotions of hospice workers; specifically, nurses and social workers become frustrated. Those embracing the social movement culture of hospice are more likely to be frustrated with the rules imposed by the Medicare Hospice Benefit, while those who embrace the bureaucratized culture of hospice are more likely to be frustrated with uncooperative patients.

In Chapter Seven I examine the funeral industry and its professional jurisdictional claims: the control over the body and the management of grief. The control over the body is stigmatizing work, so funeral directors promote themselves as experts in grief in order to manage stigma. They do so by preparing the body for viewing so the bereaved can take away a comforting memory picture, engaging in informal counseling with the bereaved and directing the funeral performance. This is where things are slightly different than the other two institutions, because challenges to funeral directors’ expertise do not come from within, but from the corporatization of funeral homes and consumer organizations. Here, I show how the business, customer service culture of the corporations reduces

professional funeral directors' ability to prepare the body, counsel the bereaved, and customize the funeral package to fit individual needs. The consumer rights culture of funeral work, represented by funeral societies, attempt to challenge the claims of the therapeutic value of embalming and viewing and charge funeral directors as not concerned with the needs of the bereaved but as exploiters of grief.

Finally, in Chapter Nine I discuss the meaning of death in these three institutional contexts, arguing that there is not one single culture of death and dying in American society or even within these institutions. In the United States death and dying is in contention, and one source of this contention is the challenge to the expertise of those who work in these institutions, whether it is from a social movement, peers within these institutions or government regulations.

The tour of these institutions will begin shortly; first, a detailed description of what I did and how I did it.

CHAPTER 2

METHODS

The Process of Discovery

Admittedly, how I gained access to all of these institutions was not very methodical. Out of necessity, I jumped around from institution to institution and organization to organization, mostly because of access constraints. Making first contact with organizations, attaining permission, waiting for approval from institutional review boards, and geographical factors lead me to gather data where I could, when I could. But my travails are less important than what I found. For this reason, instead of a chronological organization this section follows the same structure as the rest of the dissertation, starting with the intensive care unit at County Hospital and the palliative care team at University Hospital. Then I go on to hospice, starting with my time as a volunteer for Hospice on the Farm and then to my observations and interviews at Marina Hospice. Finally, I turn to Family Funeral Home, City Mortuary, and Community Funeral Society.

Why I chose the institutions and organizations I did was not very methodical either. I started out studying hospice, an organization that works with dying patients and bereaved families. After my time as a volunteer at Hospice on the Farm and publishing an article on hospice volunteers (Fox 2006), I wanted to expand on the various ways dying, death and bereavement are treated in the United States. To that end, I started thinking about the stages one goes through and the various institutions that address each stage. Medical institutions tend to sick people and are often the sites in which people discover that they are, in fact,

dying. Hospices care for those who are dying and those close to them, especially the family and their emotional states. The funeral industry tends to the dead body and bereaved family members. Because of the different tasks being performed in each institution, I suspected that there would be variation in the orientations toward death and dying.

I not only wanted variation between institutions, but within. While I had found in my research that within medicine death is considered the enemy, I had also found by watching the Bill Moyers miniseries *On Their Own Terms* that palliative medicine had a different orientation that was similar to hospice. The hospice I volunteered for was affiliated with a medical institution, and I surmised that a free-standing hospice would have less restrictions so I studied Marina Hospice. As it turns out the fact that one was medically affiliated and one was free-standing had little to do with the differences between them. I was already familiar with independent funeral homes, and when I heard of corporate funeral homes and the funeral society movement it reminded me of what has happened in medicine in which physicians have faced constraints on their practice from consumer organizations (Haug 1988) and corporate interests (McKinlay and Stoekle 2001). My goal was to capture variation in the ways that death and dying were addressed in the United States, both between institutions that pursue different ends and within institutions that have a different orientation.

Medical Institutions

County Hospital, as the name implies, is a county-funded hospital located in a large metropolitan area in California. There are several intensive care units at

this hospital but I rounded with the medical intensive care unit (MICU) attending physicians and residents. There are over 500 beds in the hospital, and while the two MICUs had a total of 16 beds (that always seemed to be full), the location within the hospital was secondary to the MICU teams, since these physicians rounded outside the MICU to other ICUs, (such as surgical), the transitional unit where patients often were transferred out of the ICU, and the general wards. While these are distinct units within the hospital, ICU physicians often crossed the boundaries with ease, especially since many of the MICU's attending physicians were also pulmonary medicine specialists and were needed for consults.

In July 2006 I began my observations of the MICU team at County Hospital. After gaining approval from the hospital's institutional review board, I observed rounds and meetings with the MICU team and sat in on "family meetings," which are usually between an ICU attending physician and a patient's family member(s), with residents or a social worker often in attendance. On a typical day two teams, each led by an attending physician, rounded in the MICU and other departments. Typically, rounds would consist of an attending physician, a resident and an intern (a first-year resident), with two attending physicians supervising two resident-intern pairs. Sometimes I started the day by shadowing one attending physician but would jump to the other if an interesting case emerged. Over a two-month period I rounded with seven attending physicians, eight advanced residents and 12 interns.

I obtained signed consent forms from the attending physicians, residents and interns I observed. On rounds, the attending physician would obtain verbal consent from patients and family members while I was outside the room, and if consent was granted the attending physician or resident invited me into the room. In addition to the ICU physicians, I sought and obtained consent from a social worker, a coronary care attending physician and a palliative care physician, and one day I rounded with one of the palliative care physicians in the hospital.² On rounds, it was not possible to take detailed notes while observing because it would be considered inappropriate. When I could, I took “jotted notes,” a couple of words jotted on a notepad to trigger my memory of an event. Whenever I found a quiet place away from the team I looked over my jotted notes and wrote down everything I remembered about the rounds and meetings into a journal, as well as questions the observations had triggered. Finally, once I returned home I typed the journal notes into my personal computer, adding any details I had remembered between the time of my handwritten journal entries and my computer entries. In addition to 119 hours of rounds and meetings, I interviewed five ICU attending physicians, an attending physician with the hospital’s palliative care service, a resident, a social worker and a chaplain that worked with the palliative care team.

University Hospital is a large teaching hospital affiliated with a major university, which includes a medical school and nursing school, on the west coast. Its hospitals and those affiliated serve over a million people a year. The palliative

² One glaring omission from those I studied were nurses. I began to obtain consent from some nurses but several of them had concerns about my study and did not consent. I concluded that it would be too cumbersome to keep track of the nurses who consented and those who did not; therefore I decided to omit all nurses from my observations at this hospital.

care team is a consult service that gives recommendations to patients' physicians regarding end-of-life care, so the patients they serve come to them through referrals. At the time I studied the palliative care team there were five attending physicians, one physician on a fellowship, a pharmacist, a chaplain, a chaplain intern and a social worker. Medical and nursing students would, at times, rotate onto the service, and many people interested in palliative care came to observe much as I did. Generally, once a dying patient was referred to the palliative care team, their path led to one of three directions. If they had a terminal illness but were not actively dying they would be referred to hospice care and discharged from the hospital. If they didn't have much longer to live they might go home to die if they had family that could take care of them and they could make it home from the hospital. For the most serious or socially complicated cases there were two hospital rooms that were specific to palliative medicine. These comfort care suites were based on the comfort of the birthing rooms and resembled a living room one would find at home, with a sofa-bed for family members' use, a cabinet with a home entertainment system, and a shelving unit with religious texts. According to statistics gathered by the palliative care team there were 351 consults in 2005.

I started my research at University Hospital in July, 2005, after receiving permission from the palliative care team and approval from the Institutional Review Board. A typical day of observations included meeting the palliative care team, observing their meetings, and rounding with an attending physician and other team members present that day. Upon meeting team members and visitors

for the first time, I gave them an information sheet that described the purpose of my study, procedures, risks and discomforts, and a statement on the limits of confidentiality. The information sheet also stated, and I orally informed them, that they are free to refuse to participate, and they may withdraw their consent at any time and for any reason. As at County Hospital, on rounds the attending physician would ask for consent from patients and/or family members while I was outside the room. For the last couple of weeks of my study I also sat in on biweekly palliative care meetings.

Finally, the affiliated nursing school offers a class in an end-of-life care that I attended for nine out of the ten class meetings for a total of 14 hours. This class mostly consisted of guest speakers who were experts in end of life care, and four of the fourteen experts were members of the palliative care team. On the first day of class I handed out an information sheet to the students, informing them of my study and that I would be audio-recording the class meetings, asked if there were any objections, and informed them that I would cease recording upon anyone's request. I asked for consent from the guest speakers in the same way: presenting them with an information sheet, asking for their permission to audio record their presentation, and informing them that they could ask me to cease recording at any time for any reason.

At University Hospital I observed 62 hours of the palliative care team rounding and meetings and 14 hours of the nursing school course. I also interviewed two attending physicians, the pharmacist, the chaplain intern, a medical student and a social worker. Between County Hospital and University

Hospital I observed 195 hours and interviewed 15 people—eight attending physicians, one resident, one medical student, one pharmacist, two chaplains (one was an intern), and two social workers.

Hospices

Hospice on the Farm serves a small New England county of about 70,000 people. According to the executive director, the hospice was formed by two medical directors at nearby hospitals in 1980. Though formed by physicians, it was a free standing hospice until about 1997, when it became affiliated with a medical institution in a medium-sized city (population about 150,000) about 40 miles away. In spite of its affiliation, it is a small hospice for a small population, with a census of about 25 patients. The staff includes an executive director, a medical director (whom I never met), a clinical supervisor, two social workers, about 25 nurses (most of them part-time hourly or per diem), a volunteer coordinator, a spiritual coordinator, and about 60 volunteers (not all are active at once).

In fall 2000 I went through the hospice volunteer training and became a hospice volunteer at Hospice on the Farm. The affiliated hospital's institutional review board approved my proposal to study this hospice, in which I would become a hospice volunteer and record my observations at hospice trainings and in the field and interview hospice workers, patients and family members, as long as I received consent from those being studied. The initial training consisted of seven once-a-week, 2-3 hour meetings, covering the volunteer role, safety and security, nursing, spiritual matters, bereavement, social work, and a volunteer panel, as well as an exit interview with the hospice volunteer coordinator. I received oral consent from those present to tape the trainings and include

the content in my study, and I informed trainers and trainees that they were free to ask me to turn off the tape recorder at any time (this was asked of me once). To supplement the tape-recorded training sessions, I analyzed written materials distributed to the new volunteers. Each new volunteer had a binder divided into sections, labeled: introduction, listening skills, personal feelings, psych/social, medical aspects, community safety, funeral home presentation, nuts and bolts, and spiritual panel. In fall 2001 I attended three additional training sessions: two pertained to the role of the social workers, and one was a panel of volunteers on which I served. In winter 2002 I went through the “bereavement training,” three 2-2 ½ hour training sessions in which established volunteers could be trained to become a bereavement volunteer for family members of deceased hospice patients. This totaled approximately 24 hours of training observations.

In addition to observing volunteer trainings I recorded about 38 hours of patient contact. In my time as a volunteer I worked with four families, but only two patients were capable of consenting to be observed. Unlike my data gathering in the hospitals, in these settings even taking jotted notes would be inappropriate, and because I worked in patients’ homes I often could not find a place to enter observations into a journal. Therefore, I spoke into a tape recorder in my car on the drive home, and later these recordings were transcribed on my personal computer. I also observed the day-to-day office work of the hospice staff for about 10 hours, shadowing a social worker and a volunteer coordinator, and attended a fundraiser for about one hour. In addition to 73 hours of observation, I analyzed blank hospice forms and records of volunteer and staff contact hours.

In addition to observations and analyzing forms and literature, I interviewed ten potential/current volunteers, three of whom were long time volunteers. I interviewed the remaining seven volunteers three times: before and after the training, and after their first patient had died. In addition to the ten volunteers, I interviewed one patient, the hospice director, two social workers, two clinical supervisors (each worked at the hospice at different times), and the volunteer coordinator, for a total of 17 interviews.

Marina Hospice, a suburban hospice on the west coast that opened in 1980, was the second hospice I studied. Though it is located in a major metropolitan area, it serves the outlying suburbs with a population of about 350,000 people. Unlike Hospice on the Farm it is not the only hospice serving this area. Because it was a free-standing hospice it did not have an institutional review board for approval, so I signed a confidentiality agreement stating that I would not record patients' identifying information and I asked for verbal consent from everyone I observed and recorded. The hospice is organized into about seven different services, the two largest of which is "patient services," which includes nursing, home health and nutrition, and "social services, bereavement and pastoral care," under which the social workers, chaplain and grief support providers work. Human resources, volunteers, development, the privacy office, development and the thrift shop are the remaining services.

In fall 2005 I observed and recorded 7 of their 8 training sessions for about 16 hours of observation, digitally recording the trainings. As at Hospice on the Farm, I announced who I was the first week of training and asked for the trainees consent to record the training, including their comments, and informed them that they could ask me to turn off the recorder at any time. From week to week, I asked the guest speakers

whether I had their permission to record their presentation for the purpose of my study. The trainings included such topics as an introduction to hospice, advance directives, cancer and other terminal illnesses, nursing, pain control, depression and anxiety, spiritual care, children's bereavement, grief, nutrition and hydration, funerals and homecare.

In addition, I recorded 20 hours of field observations, observing two nurses and a chaplain in the field, team meetings, and regular office work. I was first introduced to the staff at a weekly team meeting, at which most of the clinical staff, social workers, and bereavement workers attend to discuss the current patients and families. I informed them of my study and asked for their permission to take notes on the meetings for the purposes of my dissertation. Later, I observed two nurses and a chaplain, each on different occasions, in the field working with patients, all of whom I obtained verbal consent to study. In the field I followed the same procedure as I did when I studied the hospitals—jotted notes, journal entries, and computer entries. I also observed the annual hospice memorial service for bereaved family members, which was open to the public. Finally, I interviewed a clinical coordinator, a nurse, a bereavement counselor and an office staff person in charge of medical records and billing. In total, I recorded 36 hours of observations, four interviews, and an abundance of literature and forms at Marina Hospice. Between Hospice on the Farm and Marina Hospice, I observed 109 hours and interviewed 21 people who had an affiliation with hospice, including 10 volunteers, an executive director, three clinical coordinators, two social workers, a nurse, a volunteer coordinator, a patient, a bereavement counselor and an office worker.

The Funeral Homes and the Funeral Society

Of the three institutions I studied, gaining access to funeral homes was the most difficult. There are no institutional review boards and many funeral directors I contacted were suspicious of researchers. Fortunately I found a funeral director, an owner of a funeral home, who was sympathetic and allowed me a lot of access. Family Funeral Home is an independent funeral home in a small city on the west coast (population approx. 60,000 in 2000) that I began studying in fall, 2004. For a small funeral home it is very busy, serving approximately 450 families a year with a staff of about 10 people. At Family Funeral Home I had access to many areas of operation. I attended funerals (even pall-bearing and ushering on occasion), observing the actions and behaviors of the funeral home staff. I sat in on one funeral arrangement (but not much was arranged because the deceased had already contracted a “preneed”), observed cremations, and participated in a removal. The only thing I did not do of consequence is observe an embalming, since it is against California law which regulates who can attend an embalming.

The owner introduced me to all the staff and I informed them that if they had any objection to me studying them they can let me know, but this never happened even when I was observing the backstage work, such as cremations and removals. I only went to funerals that were announced in the local paper, as I considered these funerals in the public domain. However, I did not record the names or identifying information of the deceased or the people who were a part of the funerals. I found it difficult to even take jotted notes in an environment that was fast-paced in some areas but required respectful attention in others, so when I could I would dictate my observations into a tape recorder,

sometimes on the long drive home, and transcribed them later. In addition to 24 hours of observations, I interviewed two funeral directors, a funeral arranger and an apprentice embalmer, all of whom signed consent forms modeled on the ones approved of by the institutional review board at University Hospital. Finally, I received copies of documents and literature produced by the funeral home, including legal forms, an employee handbook and pamphlets distributed to the public.

The second site I studied was City Mortuary, a large corporate-owned funeral home in a Metropolitan area on the west coast, in spring of 2005. This is a very large mortuary, serving approximately 900 families a year, most of whom are Chinese or Italian. The funeral director allowed me access to this funeral home but on a much more limited basis than at Family Funeral Home. I could not go behind the scenes at all, and the funerals occurring on the days I observed were Chinese funerals that filled the chapels to capacity. If they were advertised they were done so in the local Chinese newspaper, which I could not read so I couldn't treat these funerals as within the public domain. Instead, I observed the staff outside the chapels and the processions from the chapels to the hearse outside and through the neighborhood. I informed the staff of my study individually, and while I did not experience an enthusiastic reception like I did from the staff at Family Funeral Home I received no objection either. Again, I dictated my observations into a tape recorder and transcribed the notes later. In addition to 15 hours of observation I interviewed a funeral director, an embalmer, a funeral arranger and a musician, all of whom signed the same consent forms offered to my interviewees at Family Funeral Home. I also collected some of their public literature for analysis, including the General Price List.

The third site of study was a nonprofit funeral society, Community Funeral Society, in the spring of 2005. This is a small organization located in a metropolitan area on the west coast. While the organization counts 9000 subscriptions covering approximately 20,000 members, it has one part-time staff person, eight members serving on the board of directors, and an office so small that only one person and the organization's records can fit in it (so I am told—I never saw the office). The staff person, who was the executive director, welcomed me and my study. Board meetings were held at a neighboring non-profit organization's office. At this site I attended public board of directors meetings and an annual membership meeting, totaling 12 hours of observations. I gathered data by dictating into a tape recorder, except for the annual meeting, in which I recorded the speakers, and transcribing my tape-recordings as soon as I arrived home. In addition to observations I interviewed the staff member and examined society newsletters.

My observations totaled 51 hours, 10 interviews, and literature from three sources. However, this was not enough data, so I supplemented my data with interviews of five additional funeral directors, a funeral education professor, a funeral home manager, a counselor/salesperson, and an embalmer/funeral arranger. To supplement data from the funeral society, I interviewed two members of a funeral society covering rural areas of the west coast and analyzed a "welcome packet" that is provided for new members. I also analyzed brochures published by the Funeral Consumers Alliance and posted on their website (www.funerals.org). Because of the limited access I had to City Mortuary, I downloaded and analyzed excerpts of brochures posted on a Dignity Memorial website pertaining to grief, as well as an informational booklet for consumers.

In total, I observed medical institutions, hospices and funeral organizations for 355 hours and interviewed 57 people who work with death, dying, and/or bereavement. I analyzed this data in an inductive process. When I started my research I didn't have a strictly defined agenda or hypotheses to test. When I started at Hospice on the Farm I had a vague idea of studying what constituted a good death, but my focus expanded shortly after I started. Early in my research, I noticed that institutions that serve the dying, dead and bereaved have to address five particular issues: A sick, dying, or dead body; the emotional state of dying patients, family and friends, and themselves; the spiritual matters of patients and family members; economic issues, whether they concern fundraising for a nonprofit organization or pursuing profit for a large corporation; and rules and regulations set down by laws, institutions and/or professional codes. As I recorded my data I developed an eye for these five issues, observing the cultures around these particular issues, and these observations come through in this dissertation not only because my eyes were on them, but they are salient issues within these institutions. For example, within medical institutions medical technology is employed to save lives, physicians train each other to show concern for their dying patients, and religion and spirituality is sometimes integrated into but more often marginalized from medicine. Let's take a closer look.

CHAPTER 3

DEATH AS THE ENEMY IN MEDICINE

The Technological Imperative, Detached Concern and the Marginalization of Spirituality

Dying and death were not always considered medical problems, and dying people were not always unseen in medical institutions. In the early 1900s, the death and dying of community members were public events. According to Philippe Aries in his classic work *The Hour of Our Death* (1981:559), “The death of a man altered the space and time of the social group and could be extended to include the entire community. The shutters were closed in the bedroom of the dying man, candles were lit, holy water was sprinkled; the house filled with grave and whispering neighbors, relatives, and friends. At the church, the passing bell tolled and the little procession left carrying the *Corpus Christi*” (559). While there was a degree of privacy for the dying, dying and death were public affairs. The public, therefore, was exposed to death and dying on a regular basis. Because dying and death were public, a person living at that time would witness dying and death routinely.

Dying and death became private affairs in the process of medicalization. Changes in American society (and elsewhere) led to changes in the settings in which people died. Between the 1880s and the end of World War II, doctors, who had already taken up the fight against disease, added advancements in medical technology and the rise of hospitals to their arsenal, thus they expanded their jurisdiction in the fight. In the fight against disease, medicalization, or “a process by which nonmedical problems become defined and treated as medical problems” (Conrad 2008:4), of dying and death occurred. Zola

([1972] 2001) examined the process of medicalization by which medicine as an institution of social control expanded its domain to include “the extension into life” (407), the control over technical procedures, access to personal areas of the body and mind, and expansion of medical expertise into the practice of everyday life. As medical technology expanded and hospital medicine facilitated the fight against disease, dying and death became medicalized. According to Aries (1981), seeking medical treatment in response to physical symptoms was not always a priority for the sick, but “By the 1880s, going to the doctor has become a necessary and important step, which it was not fifty years earlier” (564). Only in the 1930s did patients go to hospitals to die, and only in the 1950s did it become a firmly established practice.³ Cumbersome medical treatments, specifically medical techniques and equipment and the difficulty in providing adequate personal care at home, contributed to hospitals becoming the site to fight disease and dying. As a result, hospitals became “the scene of the normal death” (584). Medicalization not only involves a change in where we die, but the manner in which we die. With the battle against illness, death became prolonged:

The time of death can be lengthened to suit the doctor. The doctor cannot eliminate death, but he can control its duration, from the few hours it once was, to several days, weeks, months, or even years. It has become possible to delay the fatal moment; the measures taken to soothe pain have the secondary effect of prolonging life (Aries 1981: 585).

With death delayed and living prolonged, the status of “dying” became more pertinent and what to do with dying patients became problematic. Within hospitals, when

³ At about the same time, birth, like death was moving from the home to the hospital. In 1890 less than five percent of women gave birth in hospitals, but by 1930 about 25 percent of births occurred in hospitals and by 1960 almost all births were hospital births (Wertz and Wertz 1977).

that battle against disease was lost but the patient was still alive, dying patients were hidden and avoided by hospital staff (Kubler-Ross 1969). For example, Sudnow (1967) discussed the phenomena of “social death,” which is “marked by that point at which socially relevant attributes of the patient begin permanently to cease to be operative as conditions for treating him, and when his is, essentially, regarded as already dead” (74). Practices such as doctors filling out autopsy forms before the patient’s death or nurses encouraging patients’ family members to wait at home for further news (even though dying patients could officially receive visitors any time) are examples of social death. In another example Sudnow explains,

A very common example of “social death” before “actual” death involves the assignment of patients to beds. A patient who is admitted to the hospital in what is considered to be a near-death state: with, for example, extremely low blood pressure, very erratic heart beats, and a nonpalpable or very weak pulse, is frequently left on the stretcher on which he is admitted and put in the laboratory room, or large supply room... In several cases, patients were left through the night to die in the supply room, and, if in the morning they were still alive, nurses quickly assigned them beds, before the arrival of physicians and/or relatives (83).

Not only were dying patients avoided but the topic of death was taboo, which led to what Glaser and Strauss, writing in the 1960s (1965) called a “problem of awareness of dying” (3), or whether a patient should be told of their impending demise. Glaser and Strauss describe four “awareness contexts,” or what all the parties—patient, physician, and nurses—know about a patient’s terminal status and to what degree they are aware of other parties’ knowledge, including: closed awareness, in which the patient has no knowledge of their impending death, though the hospital staff does; suspicion awareness,

in which the patient suspects that the hospital staff thinks he or she is dying; a context of mutual pretense, in which both the patient and the hospital staff know the patient is dying but pretend otherwise; and open awareness, in which both patient and staff know and acknowledge the patient's impending death. In the 1950s and 1960s, doctors rarely told patients of their impending death because of a belief that the patient would "go to pieces" (30). All this contributed to closed awareness⁴, the norm within hospitals in the 1950s and 1960s. In general, the fight against disease, dying and death were waged within hospitals, but if that battle was lost before the patient died, the subject of death and the patient were both avoided.

The institutionalization of the battle against death in hospitals led to an amplification of an orientation to death-as-enemy, an orientation that defines death as a failure of medicine in general and the doctor in particular. The battle included three characteristics. First and foremost, the technological imperative, or the belief that if the technology is available it should be used, characterized the treatment of patients. As the fight against death included more sophisticated technology, increasingly patients died hooked up to machines and tubes. During the second half of the 20th century, the weapons in the battle against death became more potent and invasive, including the development of cardio-pulmonary resuscitation (CPR) (Timmermanns 1999), mechanical ventilation, dialysis, (Rothman 1997), and organ transplantation (Bailey 1990). With the rise of hospitals, medical techniques and technology, life could be prolonged, so within the medical profession death became not just the primary enemy, but a failure of medicine in

⁴ Other contributing factors to closed awareness includes the patients' inability to tell if they are dying, families not telling the patient, the hospital organization which keeps medical information from patients, and the patient having no allies who will help discover the truth about impending death (Glaser and Strauss 1965: 29-32).

general and the doctor in particular (Moller 1996; Comaroff 1984; Aries 1981; Parsons, Fox, and Lidz 1973). As technology became routinized so did the dependence on potentially life-saving technology (Koenig 1988). If the failure of preventing death is the primary enemy, then medical technology is the primary weapon to stave off death. The American health care system relies on medical technology, and the American public endorses this reliance (Rothman 1997).

In order to battle death, physicians must also battle the impediments, including their own emotional reactions that impede an objective diagnosis, prognosis and treatment. The norm of detached concern, in which medical professionals, especially physicians, are trained to emotionally distance themselves from patients in order not to experience the unsettling emotions that come with death and dying, was the second characteristic of the battle against death. Lief and Fox (1963) describe the process by which medical students learn to emotionally distance themselves from patients in order to cope with “emotion-laden” (13) experiences, including the death of patients. According to Robert K. Merton (1957:74) “The physician must be emotionally detached in his attitudes toward patients, keeping ‘his emotions on ice’ and not becoming ‘overly identified’ with patients. But he must avoid becoming callous through excessive detachment, and should have compassionate concern for the patients.” While there seems to be an agreement that there is such thing as too much detachment or too much concern, and Lief and Fox observe that doctors “titrate” detachment and concern when working with patients (57), the proper balance is not easily defined. However, the literature on medical education (Lief and Fox 1963) and practice (Timmermanns 1999; Zussman 1992; Coombs and Goldman 1973), suggests that there is more emphasis on detachment

than concern. As Coombs and Powers (1975) argue: “Clearly, a doctor sobbing over a favorite patient is not doctor at all.” Detached concern has been observed on the general wards (Zussman 1992), in intensive care units (Zussman 1992; Coombs and Goldman 1973) and emergency rooms (Timmermanns 1999).

Third, religion and spirituality, and specialists such as clergy and chaplains, became marginalized within medical institutions because the fight against death could not include a spiritual orientation that accommodated the inevitability of death or a redemptive value of suffering. Formerly religiously-driven institutions, hospitals became medicalized in Europe during the Enlightenment (Risse 1999). In the United States, Protestant hospitals flourished from the mid-1700s until about the mid 1800s, when Catholic hospitals formed, reflecting the needs of European immigrants. It was not until about 1890 when profit-making hospitals, owned by physicians or corporations, began to develop (Starr 1992).⁵ Medicine and religion have “conflicting perspectives” according to Holst (1985), who shows this tension in the role of doctors and hospital chaplains: “the chaplain’s role is not to explain, cure, or eliminate disease” (25) but “to bring a companionship to the sufferer” (26). This is especially true regarding pain, which Christian teachings saw in terms of punishment and redemption. As Harriet Martineau pointed out in her 1845 book *Life in the Sick Room*, “Pain is the chastisement of a Father or, at least, that it is in some way or another ordained for, or instrumental to good” (Cited in Risse 1999: 350). However, around the same time there were efforts to address pain, and according to Donald Caton (1985:499), “Since 1850 disease and pain have remained

⁵ According to Starr (1992:171) the first profit-making hospitals were small surgery centers owned by physicians with no ties to medical schools. The percentage of for-profit hospitals declined between 1928 and 1946 because the physicians who owned them converted them to nonprofit hospitals (219). In 1968 for-profit hospital chains emerged and “grew faster in the 1970s than the computer industry” (430).

predominantly secular.” As the medical battle against disease and death led to the development of new technologies and treatment, hospital chaplains became marginalized. The only job they could do, in such an institutional context, was to accommodate what physicians saw as a failure: death. If the doctor is not convinced that death is imminent, there could be tension between the doctor and a chaplain who advocates for a patient who wants a natural death (Mandzuik 1994). Chaplains are a part of the health care system, spiritual care is mandated by Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), and chaplains claim that spiritual care has a positive effect on patients’ well-being (“Professional Chaplaincy”), and studies find that patients and physicians favor including spirituality in medical practice. Still, religion and spirituality is marginalized within medicine, as shown, among much else, by a lack of medical journal articles addressing spiritual care (Weaver et al 2004).

In my research at County Hospital I found that death was treated as an enemy. There is a fight against death, and technology is liberally employed in that fight. Doctors, at times, were not emotionally affected by the deaths of their patients, and when and if they were they did not allow their emotions to interfere with their ability to serve patients and families. While physicians generally said they supported patients’ spiritual needs, they didn’t really accommodate them, and chaplains were generally not considered a part of the health care team. This is not surprising. The tensions, conflicts, and signs of change will be addressed in the next chapter, but this chapter analyzes the institutional sources of an orientation to death as an enemy in medicine, specifically focusing on the technological imperative, detached concern and the marginalization of religion and spirituality.

Technology and the Fight against Death

The primary goal of medicine is to treat an ailing body, which requires intense examination. In the ICU at County Hospital, patients undergo extensive examination so the physicians can make diagnoses and plans of care. For example, on rounds in the ICU, upon arrival at a patient's room a resident (usually the intern, a first-year resident) will present the case. The case presentation is thorough; even conditions not relevant to the disease are presented, including conditions in the range of normal such as blood pressure, oxygen levels, or a non-distended abdomen. According to one intern, reporting conditions not relevant to the patient's disease is "about being thorough," and an attending physician emphasized the importance of eliminating possible diagnoses. Another example of the intensive examination is the use of diagnosing imaging technology, such a x-ray, magnetic resonance imaging (MRI) and computed tomography (CT or CAT scan), or what Ansbach (1993:60) calls "technological cues." While I couldn't always tell what imaging technology was being used, I can say that doctors routinely depended on such technology for diagnosing conditions. For example, every morning after the attending physicians and residents met for an educational session, the team started their rounds by "looking at film," particularly CT scans and X-rays. Finally, analyses of bodily samples on the microscopic level were instrumental in diagnosing the illness, particularly infectious agents.

Once the attending physician diagnoses a patient, he or she can implement a treatment plan. However, before treatment many patients become dependent on life-support, such as respirators and feeding tubes. In these cases, doctors prolong the patients' lives artificially until they can diagnose and treat the disease, therefore they

employ technology to sustain life as well as treat. Treatments might include medicines, (such as blood thinners or antibiotics), surgery, or chemotherapy and radiation (in the case of cancer patients). If all goes according to plan, a patient, after being intensively observed by physicians and kept alive by artificial means, will have the disease treated, they will be cured, and “walk out” of the hospital.

Physicians also use technology to educate the family during the family meeting. I’ve observed variations of these meetings in terms of participants, but it usually involved the ICU attending physician and a family member. Sometimes a social worker, a translator, a nurse, residents, or attending physicians from other departments are present, and the number of family members and familial relationships vary from case to case. Generally, the attending physician runs the meeting, asking family members what they understand about their loved one’s condition and educating the family about what they do not know. One physician in particular liked to use imaging technology to educate the family: “I usually like to show them pictures. I think a lot of times it helps them understand what you are talking about.”

With this general orientation to medical technology, it is not surprising that it is the main tool by which physicians fight death. In fact, technology is not only the promise of saving a life, but patients’ deaths are sometimes attributed to a lack of access to medical technology. In the following example of a death as the enemy, a woman died when she did not have access to medical technology. One morning I arrived at 7am and met the resident on call overnight, who told me about a 49-year-old woman with heart disease and diabetes who went into cardiac arrest. The young doctor and other residents worked on the woman for four hours, administering four pressors and CPR. The resident

was upset and felt that even though she died she was young enough to have lived, saying “I don’t like to lose people who are that young.” After scrutinizing the case, the resident felt like everything possible was done for the woman. As more attending physicians and residents arrived they began to review the case, and one attending physician exclaimed suddenly, “She died because she had to wait.” As it turned out, the woman had been scheduled to have a heart catheter put in place because her heart didn’t pump very well, but the catheter was delayed because of a high number of myocardial infarctions that day—other more acute cases had priority. By the time these cases were resolved the “Cath-Lab” closed, so her heart catheter was delayed by a day that she didn’t live to see.

No one can know with absolute certainty whether the woman would have lived longer if she had the heart catheter, but these facts, which I confirmed with an attending physician and a resident, remain: 1) a heart catheter was medically indicated, 2) she did not get her catheter at the scheduled time because other cases had priority, and 3) she died before she could get the catheter. The resident added that the woman should have come to the emergency room earlier, thus she is partly responsible for her own death. In this case, the young doctor did not appear to consider that the woman was so sick that medical intervention would be inappropriate. Because of the woman’s relatively young age⁶, the doctor assumed that medical intervention was appropriate and could save her life. In the ensuing conversations, the focus is not on the doctor’s responsibility but blaming the bureaucracy that prevented the woman’s access to life saving technology, or

⁶ Generally, the younger the patient the distressing the death is for the doctors I studied.

blaming the patient for not seeking medical care.⁷ What the young doctor is being taught in this situation is that it is appropriate to fight against death, but when death occurs there are other factors to consider, such as the hospital bureaucracy or the patient's delay in seeking care, rather than the doctor's own life-saving skills. What is *not* being taught is that in even in cases of younger patients, some patients are too sick to save.

This is a pretty clear-cut case of death as the enemy, in which there was a clear consensus among the attending physicians and residents that employing life-saving technology was medically appropriate. There is not always such a consensus, and sometimes a physician will employ life-saving technology when other physicians believe the case to be hopeless. For example, for as long as I observed at County Hospital there was an intubated man with HIV who, in the words of one attending physician, was “on every type of antibiotic I’ve heard of and several I haven’t.” While this attending was comfortable writing DNR orders, the resident on the case insisted on treating the man because the underlying condition, HIV, could be treated. At one point the attending physician asked the resident, “how much longer... before you let him go?” About a month later the man was still in the ICU and other attending physicians referred to the case as the resident’s “prophesy” that the sick man would “walk out of here.” When I asked an attending physician if he believed the sick man would walk out, the attending physician replied, curtly, “no.” In spite of the fact that three attending physicians agreed that the man’s condition was terminal, the resident continued to treat because he was encouraged that the antibiotics were having an effect. In a conversation I had with the

⁷ Much of this is similar to Millman’s (1977) observations of medical mortality reviews, in which doctors focus on factors other than the doctor’s actions, such as the patient’s drinking, mental health or belligerent behavior.

resident he made the point that many health care workers, including physicians, think that if a patient is DNR/DNI, then, “Why are they here?” However, “just because they are DNR/DNI doesn’t mean you don’t treat.”

These cases illuminate the possibility that medical technology can save lives and an orientation of death as the enemy. However, the orientation to death as an enemy is a little different than previous research suggests. In one case, death was not a failure of medicine in general, because if the heart catheter had been used it might have saved the woman’s life or of the young doctor because all life-saving technologies and techniques were used to save the woman’s life when she coded, but death was a failure of the hospital bureaucracy and the woman for impeding access to a life-saving heart catheter. In another case I am not certain of the outcome since the man with HIV was still in the ICU when I ended my study, but medical technology was employed to fight death when there was a lack of consensus concerning the futility of the case.

Emotions: A Degree of Detachment

At County Hospital the physicians I observed did not engage in dramatic emotional displays at the death of their patients. Whatever they felt, it was not so overwhelming that they could not do their job. Typically, during family meetings attending physicians would display care and concern, and after informing the family members of the patient’s impending death would say “I’m sorry I don’t have better news” or “I know this is difficult for you.” Sometimes a physician would display physical affection by squeezing a family member’s arm or patting them on the back. However, they never lost their equanimity, and it seems their concern was well-titrated. After the

meeting the doctors would get right back to work on the next patient, as if they didn't have the time to emotionally "process" what had just occurred.⁸

Death and dying is so commonplace in the ICU that there seems to be a desensitization process⁹. In the process of working in the ICU, doctors become more emotionally distant from their patients. For example, in one case a woman was dying while her family was in the room. Because she was on a ventilator and other machines her family didn't know she had died, so an attending physician went in the room to inform them. Afterwards, I asked the physician if he felt anything for the patient and family, and he said, "No, though I did feel bad for the nurses." Another attending physician told me how he felt when his patients died,

Actually, one thing that is somewhat difficult, because it happens so much, sometimes I almost feel like my emotions for it has become a little less intense than I would like.... Sometimes I feel like...death should bother me more than it does.... It comes with the job and it happens so much, you have to deal with it so much, and therefore you need to develop ways to sort of protect yourself. You have to figure out ways to not get yourself too personally involved so you're not paralyzed by it.

In my observations, this doctor on rounds presents as compassionate and sensitive to patients and family members, expressing sympathy for their plight. Whatever emotions this doctor is experiencing during family meetings, they don't seem to interfere with the next task. For example, I've observed this doctor go straight from a family meeting,

⁸ I found this process interesting because, after sitting in on my first couple family meetings I was emotionally affected by the experience. However, as I observed more meetings it seemed like I was becoming less emotionally affected by the process.

⁹ According to an ICU attending physician, in the first eight months of 2006 there were 108 deaths in the adult ICU.

expressing sympathy and care, to the next case, giving orders to residents and not discussing the family meeting with them. Clearly this doctor was not paralyzed by emotions.

It is clear that there are some rules concerning emotions. Other physicians I observed agreed that there has to be some kind of control of one's emotions, and a palliative care physician at University Hospital explained the degree in which expressing sadness in front of patients is appropriate: "I think it's fine if your eyes well up with tears in front of patients... [but] I don't think you should be in a position where patients are consoling you. I don't think I should be more upset than the patient." A physician's emotions should not be so overwhelming that they cannot do their job, and they should not cause a patient to try to take care of the doctor. All of this, though, doesn't mean doctors cannot, should not, or do not feel sadness or compassion for their patients. That is a topic for the next chapter.

Religion and Spirituality: Not Part of the Team¹⁰

At County Hospital, chaplains occasionally came into the ICU but I rarely saw them talk with physicians. Sometimes I would see chaplains but they were obviously not members of the intensive care teams; in fact, during family meetings I never saw a chaplain except for the one time I rounded with a palliative care physician rather than the ICU team. One attending physician told me that when death is imminent, the process is to "call the chaplain, and that's it." While doctors often consult with each other, they do not consult with chaplains or clergy in the course of treatment. Physicians will usually not

¹⁰ An attending physician at University Hospital pointed out to me that religion is marginalized in medical institutions and I am grateful for the insight. Due to reasons surrounding confidentiality I cannot credit the physician by name.

become involved with patients' spiritual issues, in spite of the fact that, in interviews, the attending physicians said that patients' spirituality is important. However, some religious values are in conflict with those of medicine in terms of suffering. One physician told me a story about a "hyper-religious" woman whose husband was in the intensive care unit "When it was time for me to remove life support, said to me that her husband was hyper-religious, and that Jesus suffered on the cross and her husband would be happy to do the same. So I said, 'You want me to crucify him?' And she said, 'Well, it's a religious curing to be crucified and that's okay.'" I suggested that perhaps this woman saw suffering as redemptive but in medicine suffering was the worst thing that could happen, to which the physician replied, "prolonged, needless suffering is just so abhorrent to me."

While this example shows a conflict of values between medicine and certain religious traditions, sometimes doctors fail to see the use of religion, spirituality, or those who specialize in such matters. In one telling example, I was on rounds with an attending physician and a resident to see a young woman with kidney disease. The attending physician asked her what she liked to do, and the patient responded that one of her favorite things is talking to people about God. The patient then told us that she was feeling that, because of her condition and everything in her life, it has occurred to her that "it might be better I just died." The attending physician asked if she was feeling depressed and if she wanted to see a psychiatrist, but the patient resisted that suggestion so both the attending and the resident suggested she talk to a social worker. The patient agreed reluctantly and later the social worker was informed of the case. What struck me was that at no time did the doctors suggest that she talk to a chaplain or her clergy—even though the patient expressed a strong spiritual orientation and a resistance to speaking to

a psychiatrist or social worker. At one point when the doctors were busy talking with nurses and others, I asked the patient if a minister from her church ever came by to see her, and she said he did and she enjoyed those visits. Later, I suggested to the resident that she might benefit from seeing a chaplain and he said, “That’s a good idea. I’ll suggest it.”

I’m not sure if the resident ever suggested it or how he really felt about my suggestion, which may have been inappropriate. No matter: This example shows the marginalization of spirituality in medicine; in this case, the possibility of speaking to a chaplain probably didn’t occur to the physicians, even when the patient was resistant to psychiatrists and social workers and had expressed her religious orientation. In another example, a chaplain from County Hospital I interviewed who was also a part of the palliative care team argued that many in medicine do not see chaplains as part of the health care team, in contrast to palliative care which “gives the chaplaincy another element of credibility, of being a part of the health care team.” He also discussed the phenomena of “The Doctor Card,” in which doctors assert their authority to get their way, in effect saying “I’m the doctor. This is the way we’re going to do it.” Another chaplain I interviewed at University Hospital contrasted working with the palliative care team with working in other parts of the hospital, saying that working in general medicine,

Especially with the nurse, whenever there is a need or anything. So that in the case of a psych evaluation and [the patient] is very angry and the nurse comes to the chaplain for a debriefing, or just to vent.... So it’s only when the physician or nurses are in a crisis situation or everything gets tense that I’m actually interacting with them.

Outside of palliative care, chaplains and clergy are marginalized. Chaplains do not choose if, when and how to become involved in patient care or to debrief patients, nurses or physicians. Although doctors believe that spirituality is important, the medicalization of disease, dying and death has relegated religion and spirituality from a major force driving the culture of hospitals to an afterthought.

The Increased Knowledge Gap

The fight against death and dying includes some amazing technological developments—respirators, CPR, and organ transplants are just a few. With the development of technology came the technological imperative, or the idea that if the technology exists, it should be used. In order to fight death, any emotional response that prevented doctors from fighting against death must be controlled and anything that would have accommodated a spiritual understanding of dying, death and suffering had to be marginalized. To a certain extent I've found the technological imperative, detached concern, and the marginalization of religion and spirituality in my research. These are all elements of a death-as-enemy culture that is routinely reproduced on a day-to-day level in the hospital.

The medicalization of death and dying led to another phenomenon, which is a wider knowledge gap. Doctors know much more about disease, dying and death than previous doctors, but since death has moved out of the home and into medical institutions the public doesn't know much more than they did when death and dying were public affairs. Few lay people could say, with any sophistication, how CT scans, EEGs, respirators, defibrillators, and feeding tubes are supposed to work; at least, this is what the doctors I spoke to believed. Furthermore, the doctors I spoke to believed that many

people do not know the limits of medical technology. For example, one said “I think that’s one of the biggest things, is that here we have the knowledge to sustain life but we don’t have the ability to eliminate the process that’s causing the dying. Then you’re kind of in a bind.” And another said,

It’s hard for people to say “Well, you can fix this—Why can’t you fix this?” I have a friend who asked me a very simple, straight-forward question about medicine... “Why can’t you cure cancer?” And it sounds pretty simple, and then you start explaining why you realize that it’s much more difficult than that. And it’s hard for people to understand that—it’s hard for us to understand why we can’t solve certain things and fix certain things, and why we can do so much great stuff, but then certain things we can’t do anything about.

Not only does the public not understand how technology works or the limits of technology, but what technology means. For much of the public, the use of medical technology is the same thing as “care.” One attending physician told me,

I try to point out to patients and family the difference between *to* and *for*. I can do a lot of things *to* somebody, and I can do some things *for* somebody. They are different. Doing things to people—I can always do things to people.... But it’s not necessarily doing them a favor, so there’s a difference between *for* people and doing things to people, and that the technological imperative shouldn’t be mistaken for compassion.

However, the fight against death in hospitals is not the whole story. Much is changing. Part of that change is that patients are not dying alone and isolated in hospitals as much as Sudnow (1967) documented and open awareness (Glaser and Strauss 1965) is much more common. As for the technological imperative, detached concern and the

marginalization of religion and spirituality, in the intensive care unit at County Hospital there is a very strong sense that there should be less technology at the end of life, and life-prolonging technology and techniques is framed in violent terms, described as “torture” and “assault.” Doctors often feel sadness when a patient dies, and the ideas expressed by Coombs and Powers (1975) that a doctor who sobs over a dying patient “is no doctor at all” is not shared by the doctors in the intensive care unit. While religion and spirituality are still marginalized, within palliative care it is not. Chaplains are an integral part of the palliative care team, and spiritual matters are addressed by many physicians on the team. In addition to a death-as-enemy culture produced in medicine, there is a suffering-as-enemy that, with some tension, coexist in the hospital culture.

CHAPTER 4

SUFFERING AS THE ENEMY IN MEDICINE

Fighting against Torture, an Emotional Imperative and the Uses of Spirituality

As the previous chapter illustrated, the medicalization of death and dying led to patients dying in hospitals, alone and often frightened, because medicine oriented itself to fight against death. However, many people in medicine and American society came to believe that dying had become over medicalized, with patients subject to futile treatments and abandoned when there was little chance of recovery. Slowly, a challenge to this orientation toward death and dying occurred within medicine, both in terms of ideals and practice. Two examples of the challenge to medicine's orientation to death and dying include the right to refuse life-saving medical treatments, accomplished by the use of advance directives, and the rise of palliative medicine.

Death became such an enemy that by the 1970s the process of dying had slowed tremendously, stirring controversy. Patients in persistent vegetative states were often placed on life support for years, and this led to several court cases, such as the New Jersey Supreme Court case of Karen Ann Quinlan in 1976, ruling that patients have a right to refuse life-sustaining medical treatments and these rights do not expire if the patient is not competent to make such decisions. Later, the U.S. Supreme Court ruled in *Cruzan v. Director, Missouri Department of Public Health* that patients had a constitutional right to refuse medical treatment, and even food and water, if they become incapacitated (Fulton and Metress 1995). With an increasing number of patients

unconscious as they approached death, many patients have turned to advance directives,¹¹ as suggested by *Cruzan*, which are now commonplace and more or less institutionalized. All fifty states authorize living wills and/or appointments of health care agents (Fulton and Metress 1995) and some health maintenance organizations, such as Kaiser-Permanente, offer standardized advance directive forms to their patients (Kaiser Permanente 2005).

This change is not simply symbolic, affecting a small number of cases. The rise of advance directives represent new ideals, but they have also changed practices now seen in many hospitals, particularly in the Intensive Care Units. By the 1990s, physicians (in conjunction with patients and/or family members) were writing Do Not Resuscitate (DNR) orders for their terminally ill patients when death seemed imminent. For example, Zussman (1992) found in his qualitative study of ICUs that physicians limited treatment of dying patients who are considered, for one reason or another, “terminal.” Furthermore, to subject a terminally ill patient to extensive treatments is considered “torture” (11). The decision to withhold treatment, which is consonant with physicians’ ideas of compassion, challenges the idea of employing the technological imperative in search of a cure. Thus, according to Zussman, “A willingness to withhold treatment in the name of compassion requires a renunciation of the compulsive search for cure. The incurable patient creates tensions that resonate at the very core of the physician’s occupational identity” (110). The compulsive search for cure is the fight against death, thus for a doctor to withhold

¹¹ Generally there are two types of advance directives. Instructional advance directives, such as living wills, are documents signed by a competent that instruct physicians what medical care they want or don’t want when and if a time comes that they are incompetent to make medical decisions. Proxy advance directives, such as the Durable Power of Attorney for Health Care, empowers a competent individual to make medical decisions on behalf of a patient who has become incompetent (Fulton and Metress 1995).

treatment is a capitulation to death in the name of compassionate care grounded in a revulsion toward needless suffering.

The decision to withhold treatment does not typically initially come from patients or their family members, but physicians, and physicians spend a considerable amount of time and energy convincing family members that withholding treatment is appropriate. Zussman found that in cases in which physicians want to withhold treatment while families want “everything’ done, physicians are often bitterly resentful... [I]n these circumstances, physicians resist, searching for grounds to justify limiting treatment despite the wishes of patients and families” (141). Similarly, Anspach (1993) observes that dying infants are often spared life-saving interventions, based on the ideas that the dying process should not be prolonged, an infant is not yet fully a “person,” and the predicted quality of life is poor (28-32). Furthermore, after (and *only* after) a neonatal ICU staff has concluded that the infant is terminal, will they “produce assent” (92) from the parents to withhold treatment by presenting a “united front” to the parents and slanting the options in the direction favored by the medical staff, employing expert and technological authority as well as moral prescriptions. Physicians also manage anticipated and actual dissent from parents by preemptively deflecting parent resistance (136), persuading through the same means used to produce assent (authority, technology, and morality) (138), and discrediting parents’ objections by “psychologizing” them; that is, attributing parents reactions to psychological frameworks, such as the disruption of bonding or stages of grief models (142-143). More recently, Kaufman (2005) describes how doctors discuss “code status” with dying patients’ family members:

Doctors do broach the topic of code status with patients and families when they feel strongly that a resuscitation attempt would be unsuccessful and would be terrible to perform prior to death—for instance, on those who have a terminal diagnosis and are thought to be near death anyway... or on those frail elderly who have multiple, serious medical conditions indicating that the end of life is near. In such cases... physicians work to convince the patient or family “to choose” against a resuscitation attempt... (49-50).

One medical specialty that is working to change the culture of death and dying in medicine is palliative medicine. One impetus to the establishment of palliative care programs was the classic five-year Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT 1995). Published in the *Journal of the American Medical Association* and sponsored by the Robert Wood Johnson Foundation, this study found that dying patients in hospitals were often subject to treatments they did not want, including ventilators and CPR. For example, while 31% of patients said they did not prefer CPR, only 47% of physicians accurately knew their patients preferences. While Zussman’s (1992) and Anspach’s (1993) studies show that physicians sometimes withhold treatment in spite of the patient’s wishes, the SUPPORT study showed that there are still many cases in which patients do not want life-saving intervention but physicians employ it anyway. Perhaps most important is the frequency in which patients die in pain: “[F]or 50% percent of conscious patients who died in the hospital, family members reported moderate to severe pain at least half the time” (1591). The authors concluded that,

The picture we describe of the care of seriously ill or dying persons is not attractive. One would certainly prefer to envision that, when confronted with life-threatening illness, the patient and family would be included in discussion,

realistic estimates of outcome would be valued, pain would be treated, and dying would not be prolonged. That is still a worthy vision.... Success will require reexamination of our individual and collective commitment to these goals, more creative efforts at shaping the treatment process, and, perhaps, more proactive and forceful attempts at change (1597).

Palliative Medicine is one proactive (though “forceful” is probably not an applicable term) attempt at change. Inspired by the success of the hospice movement, many hospice physicians and other physicians set out to integrate the hospice philosophy in medical settings. According to J. Andrew Billings,

[P]alliative care is comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a terminal illness and for their families. Key elements for helping the patient and family live as well as possible in the face of life-threatening illness include assuring physical comfort, psychological and spiritual support, and provision of coordinated services across various sites of care (1998:80).

As of the late 1980s there were few hospital-based palliative care programs in the United States. In 1987, Dr. Josefina B. Magno of the International Hospice Institute and Dr. Gerald Holman of St. Anthony’s Hospice and Life Enrichment Center in Amarillo, Texas, met and discussed the possibility of organizing hospice physicians, and in 1988 the Academy of Hospice Physicians was organized out of a meeting of the International Hospice Institute (American Academy of Hospice and Palliative Medicine 2008). Palliative medicine grew in the 1990s. With the support of the Soros Foundation’s Project on Death in America, many of the trailblazers in palliative medicine were trained in end-of-life care and hospital-based palliative care services expanded throughout the United States (Schonwetter 2006a). In 1998, according to a survey by the American Hospital

Association, 15% of hospitals in the United States had end-of-life care services, and the 1999 survey showed an increase to 20% of hospitals (cited in Pan et al 2001). A survey in August, 2000 of teaching hospitals showed that 33% had a palliative care consult service, an inpatient palliative care unit, or both (Billings and Pantilat 2001). In July 2006, hospice and palliative medicine became a new subspecialty, granted by the Accreditation Council for Graduate Medical Education Board of Directors (Schonwetter 2006b).

How much of an impact palliative care has on the end of life is a continuing question. Steinhauser (2005) calls for longitudinal studies with patients and families to evaluate the quality of their care at certain transition points before death is upon them. This sort of study is limited, since identifying who is terminally ill before the prognosis is difficult, and patients and families may experience too much stress to participate. To avoid this stress, Teno (2005) suggests retrospective studies of “proxies,” such as family members, to measure the quality of palliative care. Contributing to measuring the quality of end-of-life care is TIME, or the Toolkit of Instruments to Measure End-of-life care (Center for Gerontology and Health Care Research 2009) an Internet-based source with instruments constructed to measure such things as quality of life, pain and other symptoms, emotional and cognitive symptoms, functional status, spirituality, grief and bereavement, and caregiver well-being (Center for Gerontology and Health Care Research 2009b). The pervasiveness of palliative care services in hospitals and the effectiveness of palliative medicine indicates the extent to which palliative medicine has not only symbolically but actually changed medical care. Because palliative care is mostly a consult service, the extent to which it pervades hospital culture and palliative care physicians actually on cases in the hospital is probably variable. Still, it is plausible

that many people experience an improved quality of life through the consults of palliative care physicians.

In *Intensive Care: Medical Ethics and the Medical Profession*, Zussman (1992) describes medicine's "two cultures." First, the culture of rights, is based on medical ethics, particularly the principle of autonomy. The culture of rights is patient-centered, with patients controlling the direction of their medical care making medical decisions. The culture of the ward, however, is often in conflict with the culture of rights. The culture of the ward emerges out of day-to-day practices in medical school and residency. The culture of the ward is focused more on the obligations of doctors toward each other as well as particular patients, in terms of what medical techniques to employ and, in general, how to treat each patient (1992:222-224). The culture of the ward is what I'm concerned with here; or, more accurately, two cultures of the ward, particularly the tension that emerges within the culture from different day-to-day practices. In contrast to the orientation to death-as-enemy shown in the previous chapter there is also an orientation to suffering-as-enemy. The core value in the orientation of suffering-as-enemy is that pain and suffering are not only to be treated, but causing pain in the course of treatment is only justified when it is done in the course of providing a cure. In the death-as-enemy orientation, technology is employed to fight death, but in the suffering-as-enemy orientation technology is removed unless it is providing comfort to the patient, and to apply life-saving technology in futile cases is considered torture. In the death-as-enemy orientation, physicians train each other to emotionally distance themselves from patients because emotions are an impediment in the fight against death, but in the suffering-as-enemy orientation physicians teach each other to empathize with the patients

and provide emotional support for each other when they are overwhelmed with the emotional burdens of any particular case. Furthermore, in the suffering-as-enemy orientation there is an emotional imperative to be compassionate and be emotionally affected by a patient's demise, for that is a mark of a true doctor. The death-as-enemy orientation marginalizes religion and spirituality in general and clergy and chaplains in particular because they are seen as accommodating death and suffering, but the suffering-as-enemy orientation embraces religion and spirituality because spiritual suffering is recognized and clergy and chaplains could help alleviate that suffering. Palliative medicine focuses on alleviating suffering, thus it epitomizes of the suffering-as-enemy orientation, but the suffering-as-enemy orientation is present in other medical specialties and hospital units, including the intensive care unit. There is still a fight against death in which technology is the weapons wielded, a degree of emotional detachment from patients, and religion and spirituality is marginalized. However, these orientations and practices are being challenged within medicine. Specifically,

1. Death, and the "failure" to prevent death, is not *the* enemy. Often it is *an* enemy, but needless suffering is also an enemy that sometimes trumps death as the primary enemy of physicians. The physicians I studied would rather terminally-ill patients die peacefully rather than subject them to futile technological interventions that might cause the patient to suffer. This constitutes not only an ideological challenge to a culture of death and dying within medicine, but a practical one in which physicians must convince family members, who often have bought in to the technological imperative, that medical interventions are futile.

2. The physicians I studied have compassion for their patients, and physicians train their residents and interns for concern. While some degree of detachment is present, the idea that crying over the death of a patient is not acceptable is no longer the case. Furthermore, physicians are sensitive to patient suffering, and physicians reinforce that idea in day-to-day practice that are witnessed by interns and residents, in effect training the next generation of physicians for concern. To be able to do this is a sign of a good doctor.

3. While religion and spirituality, thus chaplains and the clergy, are still marginalized in hospitals, they are integrated into palliative care because their work is consonant with the ideals of palliative care. Chaplains are an integral part of the palliative care team, and they play a role not by accommodating suffering as redemptive but by alleviating spiritual suffering dying patients often experience.

Suffering as the Enemy

Technology and the Fight against Death

Although technology is everywhere in medicine, there are times in which technology is not employed to fight death; rather, the patient is allowed to die “peacefully,” in spite of common resistance from family members. One physician informed me of an 85-year-old woman who was dying, and “in cases like this the family comes out of the woodwork and insists on the most expensive treatment, even though it is futile.” In cases which treatment would be futile, the physicians I observed would advise the family to accept Do Not Resuscitate/Do Not Intubate orders (DNR/DNI). In one case

I observed a family meeting, in which a resident explained to the family of a 50-year-old man with cirrhosis of the liver that his liver is not working and they could not offer any more treatment or resuscitation. I confirmed with the attending physician on the case the next day that resuscitation was a “medical issue” and could not be offered because it would not help. In an interview, this attending physician told me, “In my opinion the worst thing that can happen is for them [the patient] to have a terminal illness with pain and suffering and we don’t allow them to leave. So not allowing them to die is much, much worse, in my opinion, than dying [because] I think it’s really hard to have a good quality of life with a lot of pain and suffering.”

This “medical issue” is not just technical but ideological. The medical ethic on non-maleficence, or “do no harm,” is the guiding principle behind withholding futile care. At a “grand rounds” presentation to the hospital residents, an attending physician discussed the ethics of withholding futile care, even if the patients want it. Four standard ethical principles in medicine include (Gillon 1994): autonomy, or the patient’s right to “deliberated self rule”; nonmaleficence, or an obligation not to harm; beneficence, or providing a net benefit to patients; and justice, or the right for people to be treated fairly. The attending physician also explained how these ethical principles work together,

All ethical principles have equal value. In other words, autonomy does not trump beneficence or nonmaleficence. So patients and families have the right to autonomy, the right to choose from viable treatment options, and it’s incumbent on us... to help identify what those options are that are viable.¹²

¹² This physician supported their claim by citing California Probate Code Section 4735: “A health care provider or health care institution may decline to comply with an individual health care instruction or health care decision that requires medically ineffective health care or health care contrary to generally

Therefore, physicians have no obligation to provide futile treatment. In fact, providing futile treatment could be unethical in the eyes of many attending physicians because it is considered “torture.” For example, as a county hospital this facility serves those with severe disabilities that do not have family to care for them. In such cases many patients are incapable of making treatment decisions and they have no family to speak for them, so the authority falls to their county conservator. In one case, an attending physician explained to me that he had to implant a tracheal tube in a woman with trisomy 18 because it was ordered by her county conservator. The attending physician said, “I hate torturing people,” and the resident on the case described it as a “travesty” because a tracheal tube would not improve the quality of her life, but the doctors had to perform the procedure because the conservator had the power. In another case, the family of a woman who was brain dead had hired a lawyer because, as reported, the family did not accept the diagnosis of brain death so the attending physician had to keep the woman on life support, even though another attending physician agreed with the assessment that it would be “torture.”

The characterization of futile resuscitation as an act of violence was common. The phrase “allow to die peacefully” was often expressed in the ICU as opposed to death characterized by a futile attempt to resuscitate or, worse, the patient survives but they have broken ribs and brain damage from oxygen depletion. For example, in a family meeting I observed a social worker asking the family of a man with HIV, “do you want us to let him die peacefully or should we try to bring him back by hitting his chest?”

accepted health care standards applicable to the health care provider or institution” (“California Probate Code”). The physician also cited the American Medical Association’s Code of Ethics, which states, “Physicians are not ethically obligated to deliver care that, in their best judgment, will not have a reasonable chance of benefiting their patients” (Cited in Stamatakis 2007).

While a violent connotation of this statement may be questioned, it is supported by an attending physician who told the sister of a woman who had extensive brain damage that CPR would not be doing the woman any favors and “would constitute an assault on a dignified lady.”

The doctors I studied at County Hospital, with one exception, are not palliative care physicians, though they often take an approach similar to palliative care physicians. I never observed the palliative care physicians at County Hospital call for a palliative care consult. Once, a resident asked an attending physician if a palliative care consult should be ordered, but the attending physician replied, “No, because I believe every physician should be doing palliative medicine.” Looking at me, the attending physician continued, “I believe these palliative care doctors are doing great work, but a lot of doctors use them as a crutch.” Likewise, at University Hospital I never observed the process by which palliative care physicians are called onto a case. Judging from the patients, palliative care physicians were called onto a case when the patient was defined as “dying,” and the patients were streamlined either to the palliative care rooms or a hospice program. The palliative care physicians always stressed that they were a consult service, therefore they gave suggestions and did not usurp the authority of the patient’s attending physician. However, given that there were relatively few patients on the service, to call for a palliative care consult seems to be based on the preferences of the patient’s attending physician. The one exception I was informed of was a time when a patient’s daughter requested a palliative care consult.

In the palliative care service technology is not used to prolong life, though doctors routinely employ pharmacological technology to alleviate suffering. By the time many

patients reach the palliative care service they often have been through many life-saving procedures that turned out to have little effect against their disease, but doctors often order the life-saving technology withdrawn when the patients reach the process of dying. In fact, the common procedure is to extubate patients, or “withdraw ventilation support”¹³ when the patient’s condition is terminal. I observed an extubation at University Hospital that was supervised by a palliative care physician, who told the nurse that “your job is to make sure the patient is comfortable,” which the nurse did by lowering the air pressure and administering morphine shots.

Like the doctors I observed at County Hospital ICU, the palliative care team advised terminally ill patients to accept DNR status. During one team meeting a “code blue” was called over the hospital loudspeaker, and while other doctors were running to tend to the code the palliative care physician commented, “We don’t go to a lot of codes. It’s more like [outstretching his arms forward and raising his hands]—STOP!” In another case of a woman with ovarian cancer, I witnessed an attending physician, with a medical student, have a discussion with the patient about a “paradox.” The woman had accepted hospice—she was to be transferred within three days—but still wanted to be “full code” while in the hospital. The woman admitted it was not a “linear decision” but was comfortable with it. She characterized the hospital as “a zoo” and was dissatisfied with a previous physician, so she’d accept being DNR while in hospice but wanted to be full code in the hospital. When the attending physician said that resuscitation might cause suffering for her and her son, the patient responded that the physician “was coming up

¹³ Terms such as “withdraw care” or “withdraw life support” are becoming frowned upon, as they indicate that nothing more will be done for the patient. However, these terms are very common in the medical discourse and doctors often find it difficult to correct the ingrained habit.

with ghost stories,” even looking at me and asking “do you agree?” In an interview, the medical student expressed that the team eventually came to an understanding of where the woman was coming from, but “it took some time”:

It’s not on the trajectory that we think of. We think of wanting to go to hospice as an acceptance of what your body is doing and how death will come, and being full code is not accepting of that. And I think the way she explained it, it had to do with the context she was in. She was in a hospital, she wanted to have everything the hospital could offer and when that ran out, then she was ready to go to hospice.

While life-extending technological interventions are not common among palliative care physicians, pharmacological technology to alleviate suffering is not only acceptable but crucial. Palliative care physicians spend a great deal of time discussing what pharmacological interventions are appropriate for different patients. Conversion charts are often used to aid in determining the appropriate dose of which medication and which delivery system; for example, how strong a fentanyl patch must be used to substitute for intravenous morphine after a patient is transferred to hospice. While pharmacological technology in the pursuit of patient comfort is crucial, there is often resistance to the dosages needed to control pain. One palliative care physician said in an interview,

Sometimes we run into problems with nurses being uncomfortable with the dosages of medication that are required, and doctors who are uncomfortable writing for such dosages. So, when you’re giving four milligrams of morphine, two milligrams of morphine, they don’t have any trouble... but when the patient is getting 80 milligrams an hour, and the bolus is 80 milligrams, and you want to increase it to 120 milligrams, people get very, very

nervous, just because of the absolute amount of medicine he needs is so high. . . . And sometimes we run into patients where doctors say “I can’t write for that much medicine,” and nurses who say “I won’t give that much medicine,” so the patient is still in pain.

In the suffering-as-enemy orientation, medical technology is restricted to what can alleviate suffering; otherwise futile life-saving technological interventions is considered torture. Medical technology can be used to alleviate suffering, but at times there is resistance to alleviating suffering. This resistance shows what happens when a physician who embraces the orientation to suffering-as-enemy meets another who is embracing an orientation to death-as-enemy.

Emotions: Concern for the Patient

The literature on detached concern, as shown in the last chapter, suggests that doctors must fight to control their emotions. To do so, they must learn to distance themselves from their patients in order to keep their equanimity. How much to do so is an open question. While Lief and Fox (1963) and Merton (1957) argue that physicians must not be too distant, they emphasize detachment over concern. Coombs and Powers (1975) argue that a doctor’s emotional displays are so inappropriate that it is a threat to the doctor’s professional identity. As discussed in the previous chapter, at least one observer has argued that “Clearly, a doctor sobbing over a favorite patient is not doctor at all” (16). This statement is clearly debatable. Recent research and my observations find that doctors are better doctors if they are in touch with their emotions, and empathizing with a patient is what it means to be a doctor. For example, Williams, Wilson and Olsen (2005) found that medical students,

[N]eed additional training in personal exploration of their own experiences and coping strategies when confronting patient death. Having clinical preceptorships, positive role models and a safe environment to discuss the emotion inherent in dying and death could go a long way in preparing... students for future experiences during their medical training and careers (380).

In another example, Serwint et al (2002), in their description of a death and bereavement seminar for pediatrics residents, stated as one of their goals of their residents to acknowledge their own feelings about working with dying children. While acknowledging that emotions can interfere with delivering compassionate care, repressing or ignoring one's emotions can also interfere with quality care and can lead to burnout. Also, as shown in Shapiro's (2002) study of primary care physicians, empathy is taught to medical students in a clinical setting, with empathy understood as a "personal relatedness" with a cognitive and affective component. While the early literature on detached concern emphasized the detached side of the continuum, the modeling of empathy and teaching medical students and residents to be in touch with their feelings constituted training for concern.

At County Hospital and University Hospital, I did not observe training for detachment, but I did observe training for concern. At both settings, physicians not only demonstrated emotions but trained their residents and medical students that emotional expression, with some limitations shown in the previous chapter, are appropriate. This was also different from the desensitization described in the previous chapter by one attending physician who wished for stronger emotions around patients' deaths. As reported by attending physicians and residents, when a resident is emotionally affected by the death of a patient they are not reprimanded or trained to emotionally distance

themselves; instead, their emotional response is validated by attending physicians and other residents.

In contrast to previous research claiming that doctors must be detached in order to be doctors, the doctors at County Hospital claimed that doctors *should* be affected by patients' deaths. As the doctor who described himself as "desensitized" in the previous chapter said, "I think you have to recognize that this is still a fellow man... If death doesn't bother you, why are you [the physician] doing this?" Perhaps the strongest words expressed on how physicians should feel about the death of patients came from this attending physician:

If you can't spend time with the family and be empathetic and communicate with them and help them bridge that really traumatic moment, then you're in the wrong field. I think that's all part of being a doctor, it's doing that. It's not just pushing drugs and turning dials on machines. It's really, I think, helping patients when you can and helping families, when you can, go through something like that.

The physicians I observed in the ICU are sensitive to the emotions of patients and family members, but they also recognize their own feelings on particular matters. In an interview a resident said, "I've seen a couple people take a moment to cry a little bit, and everyone respects that, everyone gives them that space, and everyone is there for them... I've had a couple interns who were really upset about a death and apologized, and I said, 'look, if you weren't upset by this you'd be an android.'" An attending physician in another interview agreed, saying "I've had housestaff that are just in tears over patients dying, and I've told them that that's okay, that's being human, and part of being a doctor is being able to be empathetic to a situation like that, and it's an important way of connecting to the family and being able to help them." When I probed about why he has

to tell his housestaff that it is okay, even valuable, to have an emotional response to death, the attending physician iterated the challenge to medicine,

There's an expectation that physicians should be stoic and not involved emotionally with the patient and family.... It's the scientific approach where the emotional part isn't valuable—it may actually may be harmful—and that's actually not true, from my perspective. I think that's actually a valuable, important way of dealing with these things.

At University Hospital there was a similar acceptance of emotional responses to death. In a talk to medical students one physician advised the students to tend to the family and be available to them, make phone calls to offer condolences, and inquire about and think of attending funerals. Most important, “notice when someone dies” by “rounding” on them. In my observations of the palliative care team it was quite common for physicians and other team members to show compassion through a touch on the arm or a sympathetic word. At one point I mentioned the literature on detached concern to an attending physician, who responded “it's so old-fashioned to me at this point. We're all human, and acknowledging that you're a human being is important.” The most palpable emotional expressions I witnessed did not concern a patient but a nephew of one of the team members. During the biweekly palliative care team meeting this team member expressed the process by which his nephew died and what the family was experiencing. Everyone listened closely to the story and one of the attending physicians empathized by saying, “you're making me cry.” The attending physician also asked how the team member was doing, who responded, “I'm okay, but not right this minute. It's good for me to talk about it too.” After the team member informed the group the funeral was in a couple of days, the attending physician said, “We'll say a prayer for you all,” and

followed it up by an insight: “When you lose your parents you lose your past; when you lose your spouse you lose your present. When you lose your child you lose your future.”

Another attending physician, in teaching students about dying, would use poetry as a tool to reach students on an emotional level. For example, I observed a palliative care physician lecture in a nursing school course on death and dying in which the physician recited a poem called “Let Evening Come” by Jane Kenyon (1996):

Let the light of late afternoon
shine through chinks in the barn, moving
up the bales as the sun moves down.

Let the cricket take up chafing
as a woman takes up her needles
and her yarn. Let evening come.

Let dew collect on the hoe abandoned
in long grass. Let the stars appear
and the moon disclose her silver horn.

Let the fox go back to its sandy den.
Let the wind die down. Let the shed
go black inside. Let evening come.

To the bottle in the ditch, to the scoop
in the oats, to air in the lung
let evening come.

Let it come, as it will, and don't
be afraid. God does not leave us
comfortless, so let evening come.

While there are some limits, expressing sadness, even crying, is acceptable in the ICU and the palliative care service. I did not observe any physicians or others crying, but several of the doctors I interviewed reported that it happens. At the very least, some physicians express that empathizing with the patient and family is essential to being a

good doctor. This is not training for detachment. To embrace a suffering-as-enemy orientation in medicine, doctors must, on an abstract level, feel the pain the patients are in so they can work to alleviate it. Instead of detaching oneself from a patient emotionally in order to fight death, physicians must, in order to alleviate pain, feel it on some level.

Religion and Spirituality: A Major Domain

While religion and spirituality, thus clergy and chaplains, are marginalized at County Hospital, they are making inroads within palliative medicine. As Marr, Billings and Weissman (2007) argue, “Spirituality is a major domain of palliative medicine training” (169). Okon’s (2005) literature review of spirituality in palliative medicine shows that most patients have some form of spiritual and/or religious views, and spirituality is salient at the end of life. For example, patients who have a strong spiritual well-being are less likely to suffer from depression and have a greater quality of life at the end of life. Several quantitative instruments have been constructed to assess spiritual needs at the end of life, measuring such variables as one’s closeness to God, engagement with everyday life, relationships and support, and struggles of a spiritual nature. Spiritual inventories assist chaplains and others to assess patients’ spiritual needs and help alleviate spiritual suffering.

Alleviating spiritual suffering is consonant with the goals of palliative medicine. In the previous chapter I noted that one reason religion might be marginalized in medicine is due to Christianity’s history of giving meaning to suffering and an orientation toward suffering that includes a possibility of redemption. In contrast, palliative medicine aims to alleviate spiritual suffering. As Chochinov and Cann (2005) point out,

Palliative care endeavors to attend to the whole person. Inroads have been made in the areas of physical and psychological symptom control associated with advanced disease in the final phase of life, but there are aspects of suffering and distress toward the end of life that too often remain beyond the abilities of contemporary palliative care. To understand this more fully requires a careful examination of the spiritual and existential domains of patients' experiences. Although these are always embedded within the complexities of conventional symptom distress, discussing them separately... offers an opportunity to explicate these aspects of patients' suffering (S-106).

At University Hospital in the palliative care service the chaplain is not marginalized; in fact, the chaplain is an integral part of the palliative care team. For example, in one case the chaplain volunteered to talk to a very religious patient who did not trust the doctors as a way to get the patient to open up to someone on the team. In addition, a chaplain intern told me in an interview that

I'm kind of an advocate for the patient and the families to voice some of the concerns that they might not bring to the physician. Sometimes I'm less scary than the physician, and they can express feelings to me that they can't express to the physicians.

The chaplain intern also expressed fond feelings of being a part of the palliative care team, comparing it to other units in the hospital,

It's easy because that's where I'm part of the interdisciplinary team... In general medicine, it is only when the physicians and nurses are in a crisis situation or everything gets tense that I'm actually interacting with them. So there is a big difference being a part of a team. Because you see more need, and you're more sensitive to what everyone does around you.

Chaplains, and others on the palliative care team, address spiritual needs by establishing a relationship with dying patients that include a spiritual dimension. At a lecture to the nursing school's death and dying course, a chaplain who works with the palliative care team stressed that chaplains address "three core spiritual needs," the first of which is "meaning and direction,"

A dying person who has meaning and direction issues would talk about where they are going in the afterlife, do they feel that their life had meaning as they do a bit of life review, what was the good and the bad of it, [and] what they are passing down to future generations....

The second core issue to address is "belonging and community,"

Belonging and community... that kind of patient might feel grateful for care, but have a sense of low self-worth, and feel isolated and want to reach out and have that belonging and community right up until the very end of their life. So an appropriate response to them might be embracing them, affirming them, supporting them... and giving them that sense of community right up until the end.

The third of which is "to love and be loved,"

To love and be loved, and when that is out of what, that means that that need isn't getting met, they might need reconciliation, and so that's the category... what they're doing is growth in relationships.

Interestingly enough, as we visit dying patients, people bring up issues in kind of those three consolations of concern, so we call those three core spiritual needs.

The integration of chaplains and spirituality in the palliative care service is in contrast to the marginalization of chaplains and spirituality at County Hospital. Chaplains are employed at the hospital and they visit patients and families, but they are on the

margins to the point that even when patients express a need for spiritual comfort, physicians often don't hear it and pursue medical avenues to treat depression. This is exactly what happened at County Hospital, as shown in the previous chapter of the young woman with kidney disease who, from where I observed, was experiencing a spiritual crisis but was encouraged by the attending physician to seek psychological help. In the death-as-enemy orientation, religion and spirituality is thought of as accommodating the reality of death and the redemptive value of suffering. However, the role chaplains and clergy play in a suffering-as-enemy orientation is to accept the reality of death but alleviate suffering of a spiritual nature.

Convincing the Families

In my research I have found that there is some tension between the death-as-enemy orientation and the suffering-as-enemy orientation within medicine, but more importantly there is tension between physicians who, in particular cases, are promoting a suffering-as-enemy orientation to a patient or, more often, family members who have embraced the death-as-enemy orientation of medicine. The primary enemy of each particular case has its own set of tools that are not interchangeable; one cannot cure cancer with morphine or alleviate suffering with CPR. The tension between these orientations is apparent at the end of life, when a doctor has capitulated in their fight against death and will now fight suffering but family members, distraught at the prospect of losing a loved one, still want to fight death. Doctors want patients and their families to embrace the hope of medical technology when it can be used to cure, but at the same time accept the limits of technology when death is near. This is difficult for some patients, and especially family members, to do. In addition, doctors have a head start on family

members in the process of accepting a patient's death because they access the information sooner and have less emotional ties to the patient than family members.

One job of the attending physician is to educate patients and their family members that medical technology cannot save their or their loved ones' lives. An attending physician at County Hospital told me during rounds that medicine worked its way into a bind by promoting life-saving technologies instead of preventive medicine, so now patients expect a lot of technology at the end of life, even when using such technology would be futile. Another physician told me about an idea he had to make an educational video concerning CPR and what happens during a code, because "people have no clue." As to why people have no clue is beyond the scope of this study, but one reason might be related to popular culture and how that public views CPR on medical shows such as *ER*. One attending physician told me of what a colleague said to her about these shows: "They show what happens during the codes, but they don't show what happens after the codes."

In my observations at County Hospital many patients and family members would accept the terminal diagnosis of the condition and not challenge the doctors. Others, however, had a difficult time. In two cases, family members took a long time accepting the diagnosis of brain death, and one family hired a lawyer with the intent of keeping their loved one on life support. One of the most extensive cases I followed concerned a man with COPD and congestive heart failure, who characterized the doctors as "gods." The man's sons researched treatments for their father's condition on the Internet and repeatedly asked the attending physicians about treatments they had found. This was a frustrating case for the attending physicians, residents and interns because they felt like

the family was not listening to the doctors, not accepting of their father's possible demise, and pressured the doctors to engage in a futile fight against death. At one point an intern summarized to me what he wanted to say to the family: "Do I have to draw a picture for you? I can't make a heart grow muscle." This shows the physicians' frustration with the sons, who are looking at technologies that would not address their father's weak heart as an indicator that they were not listening to the physicians. How to communicate to a family that wants "everything" done to save their loved one's life when any pursuit of a cure would be futile is an ongoing issue. One attending physician thought of my research project as a way to educate the public on the limits of medical technology, saying in an interview,

I think in so many ways technology and society's expectations have gotten us to a point—and what medicine has promised—has gotten us to a point where you're talking to me today... We have a lot of hammers for nails and tools for the right job in the hospital, and they are great things when they are appropriately applied, but many times those are the wrong tools for the problems at hand and clearly there's a lot of work that needs to be done to figure out how you communicate that well.

Sometimes the suffering is so great that it is easy to convince a patient to choose alleviating suffering over fighting death. In fact, in one case I'm not sure "convince" is the right term, since the patient did not want to be in the hospital in the first place and did not engage in any observable resistance. In this case, a man with a cardiac problem who was on a bipap¹⁴, an attending palliative care physician offered a choice to the man that his breathing problems could be treated with medicine rather than the bipap, but it could

¹⁴ A bipap is a breathing machine with a mask that forces air into the lungs

hasten death. The man didn't want to be in the hospital, and a bipap was used in order to get him home. Pharmacological technology was suggested in place of the bipap in order to improve the quality of life and alleviate suffering, even if the medicine would hasten death. The man died soon after he arrived home, and this case exemplified a desirable outcome because the man died on their own terms, at home with his family. This was not thought of as a defeat by death, but rather a success in alleviating suffering.

The resistance to using medical technology when it is futile is based on the belief that it can cause suffering, and the physicians I observed at both County Hospital and University Hospital are sensitive to the comfort and well-being of their patients. This is not detachment. In fact, first, they show concern for their patients by letting them die peacefully rather than subject them to futile treatments, which they describe as "torture." Second, the attending physicians teach the residents for concern rather than detachment by emphasizing sensitivity toward the patient's comfort and well-being and empathy for the patient and family, and it is perfectly acceptable, and even expected, for a physician to be bothered by a patient's death. Third, the argument by Coombs and Powers (1975) that a doctor who cries over a dying patient "is no doctor at all" is not true today. Finally, the argument that if doctors were to be too concerned about patients they could not do their job and heal people is not supported by my study. In an interview with an attending physician at County Hospital one of them discussed suffering,

If you've got a kid who has appendicitis, you can cure him and he can lead a perfectly wonderful normal life, but he's going to have to suffer a little bit from his appendectomy operation. That's suffering too.... But prolonged needless suffering is just so abhorrent to me.

Several attending physicians told me that death is not the worst thing that can happen—needless, prolonged suffering is. This point of view represents a conflict between the culture of medicine and certain religious ideas around suffering. As Holst (1985) observes, clergy were in hospitals to bring comfort to suffering, not eliminate it. However, chaplains have been integrated into palliative care, in which there is a distinction between religion and spirituality. In one conversation between an attending physician, a fellow, a social worker and a chaplain, the attending physician reported seeing a patient who had expressed nervousness about life after death and had questions about it but did not want to see a chaplain. The attending physician emphasized to the palliative care team that the need here is for spiritual care, or the existential questions related to life and death. In this conversation the attending physician was affirming the patient's spiritual need of asking questions concerning life after death. The focus here is on improving the quality of life, which is the very definition of palliative medicine. Chaplains and spirituality are integrated into palliative care because they work to alleviate suffering and improve the quality of life for dying patients through addressing the three spiritual needs—meaning and direction, belonging and community, and to love and be loved. Rather than a religious accommodation of suffering that is at odds with the values of medicine, chaplains work to provide an alleviation of spiritual suffering that is consonant with the values of palliative medicine.

Contention over How Death and Dying Is Medicalized

The medicalization of death and dying led to a fight against death, in which death was an enemy to be conquered. Death became a failure of medicine and the doctors, so the technological imperative, detached concern and the marginalization of religion were weapons wielded in the fight. In the fight against death patients suffered physically, emotionally and spiritually, so institutional changes occurred in the form of the right to refuse medical treatment and palliative medicine. Death and dying is still medicalized in American society, for, as Conrad (2007) convincingly argues, “For demedicalization to occur, the problem must no longer be defined in medical terms, and medical treatments can no longer be deemed appropriate interventions” (7). Specifically, the process of dying is medicalized in the pursuit of the alleviation of needless suffering. While needless suffering has always been a very strong concern of medicine, it was not always a fate worse than death. In the ICU at County Hospital and the palliative care service at University Hospital, suffering was a fate worse than death.

The orientations to death-as-enemy and suffering-as-enemy, and corresponding practices, coexist in medicine with tension. That tension is most apparent when a physician, who is taking a suffering-as-enemy approach, is meeting a family who is embracing death-as-enemy. Instead of the technological imperative, many physicians are withdrawing life-prolonging technologies and techniques and applying pharmacological technology so patients can die in peace. Also, the norms against feeling and expressing sadness when a patient dies are changing. A doctor who cries over losing a patient is becoming to be seen as human, and doctors are teaching each other, especially residents, that being sensitive and empathetic is an essential part of being a doctor. In fact, it could

be argued that a doctor who is not bothered by the death of a patient is no doctor at all because they would be less capable of alleviating suffering. While religion and spirituality is still marginalized because of a historic accommodation of suffering, clergy and chaplains are integrated into palliative medicine because the alleviation of spiritual suffering is consonant with the values of palliative medicine.

CHAPTER 5

HOSPICE AS A SOCIAL MOVEMENT

The Vision

Cicely Saunders had a vision: change treatment of dying patients in British society. Dying in a hospital at the time was a lonely, agonizing, and sometimes meaningless process. The orientation to death-as-enemy in medicine in Britain and the United States in the mid 20th century entailed working on curing the disease, but when a cure could not be found the patients were often abandoned, left to die alone in hospitals, afraid, and in pain. In her first publication in 1958 in the *St. Thomas's Hospital Gazette*, she articulated her vision:

It appears to me that many patients feel deserted by their doctors at the end. Ideally the doctor should remain the centre of a team who work together to relieve where they cannot heal, to keep the patient's own struggle within his compass and to bring hope and consolation to the end (Saunders 2006:11).

Saunders' vision was inspired soon after World War II by a refugee from a Warsaw ghetto, David Tasma, who donated the first £500 to open a hospice, reportedly telling Saunders, "I want what is in your mind and I want what is in your heart.... I want to be a window in your new home" (Stoddard 1978: 97). After going to medical school and learning methods of pain control at St. Luke's Hospice and St. Joseph's Hospice (both in London), she opened St. Christopher's Hospice, the model for the modern hospice movement (Kastenbaum 2001; Stoddard 1978). St. Christopher's Hospice prioritized pain control by means of Brompton's cocktail, a mixture of drugs including

heroin, cocaine, alcohol and chloroform (DuBois 1980: 71). Pain control was important because Saunders observed at St. Luke's that "you could take the doctor's prescription for medicine 'as required' and if you interpreted that to mean 'as required for the control of pain' rather than 'when the patient is already screaming'—and gave drugs on a regular basis—then the patient's life was transformed" (Stoddard 1978:98).

Physical pain was not the only type of pain that concerned Saunders. In fact, she thought dying patients were at risk of suffering "total pain," which had psychological, social, emotional and spiritual elements that were intertwined. The idea of "total pain" came to her from a patient in 1963, who answered Saunders' query regarding her pain,

Well doctor, it began in my back but now it seems that all of me is wrong.... I could have cried for the pills and the injections but I knew that I mustn't. Nobody seemed to understand how I felt and it was as if the world was against me. My husband and son were marvelous, but they were having to stay off work and lose their money. But it's wonderful to begin to feel safe again (Saunders 2006: 253).

Saunders goes on to describe this encounter as "Physical, emotional and social pain and the spiritual need for security, meaning and self-worth, all in one answer" (253). Meaninglessness, and the "desolate feelings" that come with it, is the core of spiritual pain (Saunders 2006: 218). One of the challenges terminally ill patients face is the meaninglessness and hopelessness of their situation, and Saunders' prescription for those in spiritual pain required someone to listen to the patient. Here the belief is that one who is in spiritual pain and finding life meaningless and hopeless can be comforted by someone who will be there to listen to their expression of desolate feelings.

In just four years after St. Christopher's opened, hospice care came to the United States with the opening of Hospice, Inc. in New Haven, Connecticut. A residential facility, the hospice began home care in 1973 as well. The goals of Hospice, Inc.'s home health program included addressing the "physical, emotional, social, and spiritual" needs of cancer patients¹⁵ and family, aiding a patient to experience "death with dignity," and address families' bereavement (Lack and Buckingham 1978:21). Like in Britain, hospice opened in the United States because of the inadequate care dying patients received in the medical system. In their evaluative study of Hospice, Inc., Sylvia A. Lack and Robert W. Buckingham III stated in their literature review,

The Hospice program has evolved in part as an attempt to compensate for the inadequacies of the present medical system, acute-care hospitals, and physicians in relieving the physical distress of the terminal cancer patient. At present in our society, there is slim prospect that the average terminal patient suffering from pain will find complete relief. Analgesic dosages are generally standardized and are seldom calibrated to meet the patient's individual needs; scheduling of pain-relieving medications is also seldom suited to the patient's requirements. The patient is thus often sentenced to pass through consecutive stages of sedation, uneasiness, and intense suffering. Narcotics prescribed to be given when needed... are often withheld by members of the medical staff to avoid addicting the patient and they are seldom administered before the patient is in a state of acute distress (Lack and Buckingham 1978:179).

As in Britain, U.S. hospices also tended to the emotional needs of the patients. In her discussion of the dynamics of dying, Munley (1983) describes the patient experiences

¹⁵ Today hospice not only serves cancer patients but anyone with a terminal diagnosis of six months or less.

as a set of dialects, in which “one swings between competing thoughts and feelings: wanting to hang on/wanting to let go; hope/resignation; fantasy/reality; dreading death/wanting it to be over”¹⁶ (148). Patients, according to Munley, move toward a synthesis often in a process of “life review” (171) in which they try to make sense out of their predicament. Hospice caregivers are charged with the task of providing emotional support while the patient synthesizes two polar emotional states, with the goal of finding meaning and peace.

Spiritual dimensions were also the task of hospices in the United States. In their 1982 statement “Standards of a Hospice Program of Care,” the National Hospice Organization addressed the need to address religious pluralism in the United States:

Hospice care is concerned with the dynamic process of religion, that is, with binding together, tying up, and tying fast. On the intrapersonal level, Hospice endeavors to support the integration of human personality in the face of the physical deterioration in impending death.... In regard to the eschatological dimension of human life, hospice care affirms each person’s search for ultimate meaning by respecting and responding to each individual’s personal truth (cited in Munley 1983:229).

This was a time when the “death awareness movement” (Chaban 2000:4) was gaining momentum in the United States, highlighted by Elisabeth Kubler-Ross’s seminars on death and dying (Rossman 1977) and her seminal study *On Death and Dying*. Though she did not establish hospices, Kubler-Ross endorsed the hospice movement as “the finest organization for change in this country today” (Stoddard 1978:

¹⁶ Munly begins her chapter from a quote from Leo Tolstoy’s “The Death of Ivan Ilych”: “From the very beginning of his illness, ever since he had been to see the doctor, Ivan Ilych’s life had been divided between two contrary and alternating moods: now it was despair and the expectation of this uncomprehended and terrible death, and now hope and an intently interested observation of the functioning of his organs.”

228). Hospices started opening all over the United States, and by April of 1977 there were 50 hospices in the United States (Stoddard 1978) and in 2002 there were over 2200 hospices in the United States (“Hospice Facts and Statistics” 2006). The National Hospice and Palliative Care Organization estimates that 1.3 million patients utilized hospice services in 2006, up from 495,000 in 1997, and 36% of deaths in the United States were under the care of hospice (National Hospice and Palliative Care Organization 2007).

Cecily Saunders, to some extent, succeeded in her quest to change the treatment of dying patients. Instead of dying in hospitals in pain, alone, distraught and hopeless, many patients are dying at home with their pain controlled. The control of physical pain allows them to address emotional and spiritual dimensions of pain with their families and other hospice workers. This is the hospice social movement, which has helped create the orientation to suffering-as-enemy, and addresses physical pain and discomfort, emotional distress and spiritual crises¹⁷. However, in order for hospice to build a social movement culture, it had to draw upon the expertise of other disciplines, especially medicine, social work and religion. While other social movements challenge the expert knowledge institutional actors espouse, the hospice movement used that knowledge for different ends.

Physical Pain and Discomfort

Rather than employing medical knowledge to cure a disease, hospice applies medical knowledge to alleviate pain and discomfort, and in these cases nurses take the

¹⁷ Cicely Saunders’ idea of total pain included social and psychological pain as well as physical, emotional and spiritual. However, I’ve not seen a differentiation between psychological and emotional pain, so I’m not addressing psychological pain here. Furthermore, the social component of total pain is not addressed here since the process of addressing emotional and spiritual pain encompasses the social component of pain.

leading role. Both Hospice on the Farm and Marina Hospice attend to the patient discomforts arising from pain, elimination, breathing, and personal hygiene. The first priority is pain control, since one hospice belief is that dying patient cannot attend to any other matter until the pain becomes bearable. In order to address patients' pain, nurses at both hospices will take a pain assessment by asking the patient to locate where the pain is on the body, how often they feel pain, and rate the intensity of their pain on a 0 to 10 point scale, with 0 being "no pain" and ten being "worst pain." In addition, they will ask for the quality of the pain, including duration, a description of the pain (i.e. "worse when I move" or "comes and goes"), and the type of pain ("visceral," "bone pain"). Mild to moderate pain (1 to about 4) is usually treated with nonopioids analgesics, such as acetaminophen (Tylenol) or ibuprophen (Motrin). For more severe pain opioids might be necessary, including morphine, which was described by a supervisor at Marina Hospice as "the gold standard, it is the best." A nurse at Hospice on the Farm also praised morphine as

a wonderful drug, we love it, it is the best thing but there are a lot of fears out there... it comes with a bad rep, people don't want to get addicted to pain medication, and there's been studies on people with terminal illnesses, that they don't get addicted, and they do not get a high from these medications, they get pain relief from the medication. There also is a problem with, well, if you use this now, what's gonna help me later? And they don't realize that there is no ceiling on morphine.... [W]e have people that have gone up to 100-300 mg/hour of morphine.¹⁸

¹⁸ While getting addicted or high is not much of a problem for hospice patients, morphine can have other unpleasant effects, including seizures, nausea and hallucinations, so other opioids or nonopioids are often used to control pain.

As hard as hospice works on pain issues, not all pain can be controlled.¹⁹ A nurse at Hospice on the Farm said “We never say that ‘we’re going to take care of your pain totally. You’re not going to have any pain.’ We can’t promise that. You know I will go in there and say I will do my best to make you as comfortable as possible.” Also, patients don’t necessarily want all the side effects that come with 100% pain control, such as sedation, nausea and constipation, so they are content with being in some pain. A supervisor at Marina Hospice said,

[W]e kind of customize the pain relief regimen for the type of pain the patient has. We also have a lot of questions about what’s important to them, what is an acceptable or tolerable level of pain for them. Some people will say “well, I’d rather not take any breakthrough medication unless my pain level is above a level four or five. I’m still OK, or I can function, or I can tolerate it.” But others will say “No, if it’s a level two, I want medication to relieve that pain.” So we want to customize it according to what kind of pain they have, and what their own personal desires are.

There are also cases in which a person dies in pain. In an interview with the Hospice on the Farm director I asked her about patients committing suicide, something that she is generally opposed to, but “there are some times where I do agree with it personally because that death is so horrible and we are not able clinically to fix that. I mean, there’s like 5% of patients that have, who have intractable pain and I can’t make that different. And in those cases, I think that if they want to choose that, I think it’s okay.”

¹⁹ Even though hospice workers said that not all pain can be controlled, a pharmacist at University Hospital told me that if all else fails, pain can be controlled through palliative sedation.

While pain is the primary physical issue, there are other physical matters that are important, such as elimination. Constipation is one main side effect of opioids, so hospice nurses are particularly aware of their patients' bowel movements. Hospice workers treat constipation as soon as a patient is prescribed opioids. A supervisor at Marina Hospice said, "We automatically have a bowel regimen we've put people on whenever an opioid is ordered because... constipation is almost inevitable. So we proactively act to prevent it rather than waiting until it turns into a big problem." A nurse at Hospice on the Farm emphasized what a problem that can be,

If you go into a patient's home and they said "I haven't moved my bowels in a week," please call us right away. Sometimes the patients forget that we stress that to begin with that morphine is constipating. Even though you're not eating as much, you still need to move those bowels. That's really important. We put people on bowel regime along with the morphine such as routine laxatives. That's just very important.

Patients with lung cancer, pneumonia, or Chronic Obstructive Pulmonary Disease (COPD) often have trouble breathing. Often, these patients are on oxygen, which might help but often does not solve the problem completely. One of my patients, an 80-year-old woman with COPD, was on oxygen but still tired easily. In my first meetings with her she said, "You know, John, the worst part about it is you're still young in your head." This patient loved to cook and go out but rarely did so, and as the weeks progressed her breathing became more difficult and she developed chest ulcers, which put her in the hospital and off of hospice. Another concern surrounding breathing is at the end of life. For many patients the breathing becomes erratic, ranging from short, quick breaths to very long breaths, to the point where the patient does not breathe for a long time. Most

distressing for family caregivers is the “death rattle,” a sound caused by congestion in the throat and lungs that cannot be coughed up. Often this is addressed by repositioning the patient and elevating the head. One case that I heard discussed during team meetings at Marina Hospice was a wife and husband were admitted on the same day. The woman died first and her daughter, as was reported, became distressed about the death rattle and felt like her mom drowned to death. When the man had the same experience, the daughter “freaked out” and called 911.

Many hospice patients can no longer take care of their personal hygiene. They are often bed-bound and cannot use the bathroom on their own, bathe themselves, and change their bed sheets. Because of these factors (as well as those related to the disease and medications) patients may experience skin problems such as rashes and bedsores. The skin care regimen for Hospice on the Farm includes changing position every two hours, padding bony areas with pillow, changing clothes and linens regularly (particularly if they are wet or soiled), massage, and bathing. If these interventions do not work a skin protective barrier is often used. At Hospice on the Farm volunteers were forbidden to do personal care, such as lifting patients, changing diapers or linens, or giving baths because it was “a liability issue.” These duties are mostly done by the family caregiver or home health aids, though nurses and social workers sometimes assist. One of my patients at Hospice on the Farm said that the hospice workers “come and wash me down. That was an experience, undressing yourself before a total stranger. And then I thought to myself... ‘Why am I reluctant?’ I overcame that hindrance. And then they wash me down. They keep me clean.”

Volunteers at Marina Hospice were allowed to provide personal care and are instructed how to do so in their volunteer training. In the last week of training, Marina Hospice, gave a “show and tell” of medical equipment one may see in the home of a hospice patient and demonstrated proper lifting techniques and how to make an occupied bed. The handouts for this section of the training included operating a hospital bed, assisting with dressing and undressing, and how to give a bath. I asked a supervisor whether volunteers were allowed to do this care, and she said “Yes, because they might have to help the patient to the bathroom.” When I informed her that at my previous hospice patients were not allowed to do hands-on care because of the liability issue, she responded that there is a risk of liability at Marina Hospice as well.

Spiritual Crises

Much like hospital chaplains, hospice chaplains’ main concern is spiritual suffering. The only difference I found between the hospices pertaining to matters of spirituality pertained to the centrality of the spiritual care coordinators. The chaplain at Marina hospice worked 20 hours a week and had a caseload of 13-20 patients. I saw the spiritual coordinator at Hospice on the Farm twice, and once was at the volunteer training. I never saw him in the hospice office, and while he had a desk it was always bare, except for maybe a clock or picture. I attribute this to the larger census of Marina Hospice, which had between 30 and 40 patients at a time compared to 20-25 at Hospice on the Farm.

For some patients near death, spirituality becomes central in their lives. Terminal illness often motivates patients to contemplate the meaning of their lives, and hospice

provides services to assist patients in doing so. In hospice spirituality is distinguished from religion; religion is institutional while spirituality is the search for meaning and purpose in one's life. As Hospice on the Farm's chaplain said during a presentation on spirituality, "So the word that we use tonight... is the word spirituality. And it's as if the religion which is more of an end to a means in my own growing up, is more of a means to an end of the spiritual journey. I say that appreciating traditions and appreciating the ones from which I found and the ones to which I belong." Therefore, while institutional religion can be one flavor of spirituality, spirituality does not necessarily include institutional religion. Furthermore, according to a handout from Marina Hospice, "One can be very religious and observe the rituals of their organization but not be very spiritual. On the other hand, a person can be very spiritual but not be a member of an organized religion." For many of the dying spirituality—finding meaning in one's life—is important because time is running out. Not everyone is interested in exploring spiritual matters, and some patients explore them with people not affiliated with hospice, so the chaplain at Marina Hospice sees about half of the patients.

While spirituality and religion are different, for some patients the meaning of their lives is mediated by institutional religion. I observed a chaplain's meeting with a Lutheran family, a man in his sixties with prostate cancer, and his wife. On our way the chaplain informed me she would be doing communion for them and wanted me to participate. I expressed some reservations because I am not a Christian, but she wanted me to participate to avoid a potentially socially awkward situation if I was only observing and not taking communion, and she alleviated my reluctance when she said "It's just bread and wine," framing the meaning of communion for me in non-spiritual terms. The

hour-long meeting focused on the family's physical and emotional state, their relationships with friends and visitors, and his anger at God. We then took communion. This is something that the patient wanted, and he and his wife were familiar with the rituals, including reciting "The Lord's Prayer." I cannot say exactly the meaning he found in this ritual, since I did not ask, but his enthusiasm of taking communion and knowledge of the ritual showed me that his Lutheran faith was, in his belief system, a conduit to his connection to Christ, and for him that was meaningful.

In this case, the man is finding the meaning of his life through the structure and rituals of institutional religion. Religious institutions not only provide meaning but they also shape how people die. In my volunteer training at Hospice on the Farm a Catholic layperson presented to the volunteers,

In 1995, the National Conference of Catholic Bishops published "The Ethical and Religious Directive for Catholic Health Care Services" to provide guidance on certain moral issues that Catholics would be facing today. There are a few excerpts from that document: "We are not owner of our lives, and hence do not have absolute power over life. We do have a duty to preserve our life, but that's not absolute either. We may reject life-prolonging measures that are insufficiently beneficial or excessively burdensome." There are two extremes to be avoided. On the one hand, an insistence [on] burdensome technology, even when a patient may legitimately want to forego it. Sometimes the medical community or the patient's family, not wanting to let a patient go, will insist on these things... On the other hand, the withdrawal of technology with the intention of causing death is to be avoided.

Some patients do not embrace a particular religion, so they find meaning in other ways. To the spiritual coordinator at Hospice on the Farm this is most important:

Not to have faith is, to me, it doesn't mean that we don't have meaning. You know that the atheist or the agnostic or whatever, often has found meaning but not on a particular religious or even a spiritual path. So I think we need to listen to that as well, because, for me, "atheist" may mean one thing and it may not mean that to the person at all.

The social workers at both Hospice on the Farm and Marina Hospice conduct a "spiritual assessment" of each patient at intake. At Hospice on the Farm the intake form includes a lot of questions regarding religion, but the last question reads, "Does the patient/family have concerns or wish to discuss issues related to the meaning of his/her life, forgiveness, leaving a legacy, how he/she sees him/herself, or similar topics?" A social worker at Hospice on the Farm told me during an interview,

I have to tell you. When I first took this job and I saw that I was supposed to fill out this spiritual assessment on everybody I felt a little awed by that. Somehow I was supposed to make a judgment on people's spirituality [laughs] and fill out a form about it of all things. But over the years I see it as just, something that should be a part of every social service. Because spirituality is not something separate from psycho-social... I think, my definition of spirituality is very broad in terms of about what has some meaning in life and doesn't necessarily mean what church they go to. So it fits very well with hospice because what we are talking about is making meaning, making something mean something.

Four particular spiritual matters, according to the chaplain at Marina Hospice are often central to patients: why they have a terminal illness, unfinished business, the afterlife, and the legacy they will leave. However, the question of why they have a terminal illness is not a "theological discussion"; rather it is an expression of anger, as the chaplain at Marina Hospice explained,

They are not asking why, but what it really is, is a statement of protest. People wave their ontological and existential fist in the air and say “Why is God doing this to me? God damn it!” And so basically, the job of the [chaplain] is to say, “I don’t know. I don’t know why. Tell me what it feels like. Tell me what’s happened...” and so we help them unpack it.

Another spiritual matter is related to unfinished business. Finishing business is one of the components of a “good death” that the hospice director expressed in an interview, “I think most of us want to be at home, we want to be pain-free, and we want to have finished business. I think those are the common components. I mean, I know some people who choose not to finish business and they don’t, and that’s a good death for them that nobody forced them.” While I didn’t observe anyone forcing a patient to “finish business” (it probably wouldn’t work), there can be some stress on hospice workers when business cannot be finished. One long-time volunteer expressed her anger when a family decided not to tell the patient that she was dying,

Yeah, the main thing is that I saw that everybody kept it a secret from the person who was dying. And that made me angry. I felt that a person who is dying, number one, is entitled to know they’re dying, so that number two they can finish up what they need to finish up before they leave. And uh, if they’re not told they’re dying, if everybody pretends they’re getting better, then this deprives them of the opportunity to do their own completion work. And hospice provides that opportunity, to get in there and say “okay, you really are dying.”

Because hospice as an institution encourages an open awareness context, in which both the patient and those caring for him or her know about the patient’s terminal status (Glaser and Strauss 1965), this situation is rare. An open awareness context allows for the possibility of addressing unfinished business, and the social workers often ask patients if

there is any unfinished business for them. I asked a social worker why addressing unfinished business is important:

I think there's two reasons, on both sides. One is the person who is dying... seems to have the need to ask for forgiveness for those they hurt and to be forgiven. That's sort of one of the basics and it really is true, I see it all the time... And for the person that's going to be left behind I think almost more important is a chance to rectify their relationship because they're going to go on and they're going to go through bereavement, and bereavement and grief, is very complicated when there's things that have been not, that have been unsaid, and things that are left up in the air. So it's, it's a sense of making things right for both sides of the relationship, in a way that can help the person who is still living go on live a life that has more meaning and the person who is dying have a chance to feel forgiven.

Another pertinent spiritual matter concerns the afterlife. When I volunteered at Hospice on the Farm I heard some stories of the hospice having to find clergy who would ease patients' anxiety about the afterlife. As I was told, some patients had some anxiety that their destiny was hell because of something they did years ago, and their clergy would not reassure them that they were not going to hell and in some cases were told that they were. For example, I heard this story from a volunteer trainee at Hospice on the Farm,

The hardest death I've ever been personally involved in was my mother-in-law, who died at 99. And we were very close. She was a very, very religious woman. Attended church until the last year of her life... and she disclosed to me in the last few days that she was afraid. And I asked, I tried to elicit what her fear was. Her fear was because of something she had done as a young woman she was going to hell. And I really didn't know how to deal with that and I asked

if she would like to talk to her minister about that, and she said that she would. So I called the minister and I told her what mom said to me, and asked her to come over, thinking that she would reassure her that she wasn't going to hell. And she didn't. She said "I can't tell you you won't go to hell." And my mother and law went out struggling and screaming because of the fear, because of faith. And if you hear some anger in me, it's real because this woman did not deserve that. She deserved the comfort of belief, and redemption.

And this was the spiritual coordinator's reaction to that story,

I think that if religions are about anything [it] is about forgiveness, it's about the ability to move on, it's about acknowledging our imperfections as people and that we don't have to be continually haunted by our [mistakes].... Assure them, that any of us can move on from those things in our past. Maybe we can't let go but something beyond us can.

Finally, there's a matter of legacy. Some patients feel like the meanings of their lives will be enhanced by what they leave behind for others. The chaplain at Marina Hospice discussed this issue,

What is their legacy? Not only legacy in terms of material interests, but their spiritual legacy. What do they want to pass on in terms of photos, and memories, and values they pass along, their values legacy. Being able to write a letter to the family saying "this is what we believe in. We believe in education... or that we believe in honesty, or standing up for the downtrodden, Justice"... or our identity as a family.... So listen to what their legacy is.

One of my patients at Hospice on the Farm was a man who wrote poetry and would share his poems with the volunteers. Volunteers would read his poems out loud to him and he would give volunteers books of poetry. Just as important is the volunteers were receiving his poetry; in effect the volunteers were receiving his legacy. Marina

Hospice has a rather unique volunteer who is a video biographer. He offers the opportunity for dying patients to make videos that focus on the story of their lives so future generations can watch. At the volunteer training he described his first case, which was very difficult. The subject was a man in his 50s who had cancer and wanted to leave a video biography for his four-year-old son. The man, however, had his mandible and tongue removed so he couldn't speak. So to deal with the problem,

He'd sit at his computer and type out what he'd want to say.... He typed out a whole script, and we did the whole thing in photographs, and he typed out the whole over-voice, and I did it but it was all his words and it was preserved for his four-year-old son. And they did play it at his memorial service, and there wasn't a dry eye in the house, including me.

Much like anyone else, dying patients find meaning in their lives through their relationships with other people and/or with God. Dying patients, sometimes, feel a need to solidify those relationships so that they can understand their lives as in relationship to others. Hospice assists in this process by listening to patients' life stories so they can achieve "closure." The meaning of life, then, is constructed through relationships with others.

Emotional Distress

In general, the emotions of dying patients that hospices tend are fear, anger and depression. Not all patients are afraid of death and dying and some do not become anxious when contemplating their own death, but many experience fear and anxiety concerning what will happen after death, dying in pain, and dying alone. One volunteer at

Hospice on the Farm discussed a patient she had who “was who was frightened but wasn’t about to let anybody know it,”

She feared being forgotten, as I guess we all do, saying in one of her last clear statements to me “what’s going to happen to all that’s me? What will become of my knowledge, my talents, my memories, the essence of who I am? Who will remember me?”²⁰

Fear of dying in pain is another issue. In one of my interviews with a volunteer trainee at Hospice on the Farm I asked how she would like to die, she said “quick... and as painless as possible.” A Catholic layperson who presented at the spiritual panel at Hospice on the Farm also discussed this,

[W]e are all afraid. If you ask most people that are dying... they are afraid of the suffering, and the pain that’s proceeding the dying. So my sense is that when people say that they are just saying “I want to go quickly, I want to go with my boots on” because that way you don’t suffer.

The fear of dying alone is common. None of my patients expressed the fear of dying alone, but family members and other hospice workers expressed this fear. A volunteer at Hospice on the Farm discussed how one of his first patients, whom he happened to know from years before, died in a nursing home,

It would have been better if he could have died at home with his family instead of just some nursing home surrounded by a bunch of strangers... I mean in the room there was not one picture. I mean, I had a picture of him that I printed and put on his wall of him that I had taken 25 years ago, or somebody had taken. So um, I wish he would have been with a family at home instead just in some

²⁰ These questions also relate to matters of spirituality, discussed earlier.

nursing home in bed with a roommate and really, nobody.... I bet he was lonely there.

Anger is another emotion dying patients may face, and it is one of the five “stages” dying patients go through, according to Elisabeth Kubler-Ross in her seminal work *On Death and Dying* (1969). Often, anger is directed at medical institutions, caregivers and hospice, such as this case that was described to me by a social worker at Hospice on the Farm,

This woman I visited yesterday who is just so, just very angry that we are involved with her. We represent the end of her life, she’s not ready for the end of her life, and so stays with the anger. What else has happened? Where, how did she get to this place? And then she begins to talk about her daughter that died of a misdiagnosis of cancer. And all this anger toward the medical community is really spilling more from her love from her daughter. And then we talk about love she has for her family, and then you begin to talk about what’s real instead of, you know, “You awful people are coming in here to watch me die.”

In my work at Hospice on the Farm I do not recall a patient expressing anger at me, the medical establishment or God (some very common targets). The only hospice patient I met that discussed anger was the man at Marina Hospice during the chaplain’s visit I discussed earlier. When the man expressed that he was experiencing anger at God but was afraid to express it to God, the chaplain replied, “God has very big shoulders.”

Another stage Kubler-Ross discusses is depression, resulting from losses patients have experienced and those they anticipate, including loss of life. According to a psychiatrist who consults with Marina Hospice, some depression has a normal course to run, but if a patient’s emotional state is not improving over time, or gets worse, interventions may be required. Depression was often reported in the form of a patient

making reference to suicide. Patients often talk about suicide, but most do not carry it out. Instead, many patients discuss suicide as a way of expressing how depressed they are.

One Hospice on the Farm social worker discussed patient suicide,

[T]hat's an area that's pretty gray in our field because people talk about, you know, wanting to end their lives....I was with a patient this morning, and you know up on the [hospital] floor, and one of the nurses came in... who really wasn't in sync with hospice. This patient's in the hospital to die and she came in, and then she said "well, did you have a good night last night?" and she says "yeah, I wish I'd never woken up," and she says "what? Oh my goodness, you should just be—you're going to be fine." And she just looked at her. Well that's not what we say right now. And she said "well, I hope that we can help you find a way to sleep better," and she said "yeah, get Jack Kevorkian."

Fear, anger, and depression are common emotions that hospice workers develop strategies to manage. In my observations I found that four strategies included: showing sympathy and concern, "sitting with" patients, the use of adjunctive therapies such as massage and music, and medication.

While many hospice workers tend to the emotional needs of patients and families, the disciplinary expertise, to a large extent, comes from social workers. At Hospice on the Farm, volunteers were trained to sympathize with the patient and applying certain skills. Sympathy, or "one person's feeling for or with someone else experiencing a plight" (Clark 1989:139), was taught at a volunteer training session by a social worker. Each volunteer had a sheet of paper torn into four sections, and each section was divided into four squares. On the first section they listed four people in their lives (spouse, friends, or family), on the second section they listed four things they liked on the third

section the volunteers listed four roles they played in life, and finally on the fourth section they listed four activities. After they listed four of each category, the social worker told them to give up one person, thing, role, and activity, which left them with three of each category. Second, the social worker had the volunteer coordinator look at each pile each person had and decided which one to take away. Third, the volunteer coordinator took one from each category without looking at what was left, and as she did this the social worker said “notice how you feel when she is taking that paper.” That left the volunteers with one from each category. This exercise conveyed what someone experiences in the course of a terminal illness. At first, they may need to choose what they have to give up. Second, a doctor or someone in power tells them that they cannot do, be, or have something anymore. Finally, the body gives out to the point where the sick person becomes incapable of having a particular person, thing, role or activity. From this exercise it is easy to feel for a patient and see how they might become scared, angry, or depressed about their losses.²¹

“True listening,” (or sometimes called “active listening”), is another skill taught to hospice volunteers. In general, true listening involved accepting what the person was saying, focusing on how the person felt, asking open-ended questions, seeking clarification, and summarizing what the person had said. Actions such as giving advice, minimizing the problem, changing the subject, and “Me-too-ism” were considered hindrances to true listening. The volunteer trainees able to practice their listening skills in an exercise by pairing up with someone and listening to their partner talk, for five minutes, about their first experience with death. After each partner had a turn, the group

²¹ I also described this account in an earlier publication (Fox 2006).

came back together, introduced their partner, and described their partner's first experience with death.

In my time as a hospice volunteer I have seen "true listening" in action. At one of my meetings with a patient a nurse came by to check on the patient, and in her interactions with the patient she asked open-ended questions, showed she was listening by making eye contact, and sought clarification. Another time, while observing the social worker interact with patients and family members at a hospital, I observed her focusing on the feelings of the people and asking open-ended questions. A volunteer who served on a panel at a volunteer training relayed how she was able to help her patient with her anger simply by listening:

As I learned from this class, simply being there, listening, affirming, reflecting, became the focal point of her week. I saw her sometimes two, maybe three times a week, for usually about two hours at a time. It brought, I know for a fact, peace and calmed a turmoiled soul... In squaring my shoulders and accepting the weight of her anger and her fear, I let her just say whatever she needed to say and not take it personally.

In contrast, at Marina Hospice I did not observe these techniques, with one exception. On the chaplain's visit to a home I observed her making eye contact, asking open-ended questions, and seeking clarification. I also saw that listening techniques were touched on in the volunteer training binder in the bereavement section, but they were not emphasized in as much detail. However, I also observed two nurses on home visits and I did not see either one of them engage in true listening as taught at Hospice on the Farm. Instead, I observed them carrying on conversations with patients and family members while taking notes and setting up equipment, and one nurse engaged in "me-too-ism." It

is not that the nurses at Marina Hospice were not being supportive, but they did not engage in these active listening exercises.

Another practice, particularly concerned with dealing with fear, is “sitting with” a patient. Sitting with a patient involves sitting at the patient’s bedside and just being there. The person’s focus is on the patient and what they are doing, even if the patient is not conscious or has dementia. It is thought that this kind of connection alleviates the patient’s fear of being alone and the family’s fear that their loved one will die alone. In my time volunteering for Hospice on the Farm I had a similar experience that I shared with some volunteer trainees:

One morning I was in the hospice office [and] somebody asked me if I could go to the hospital and sit with somebody because the family didn’t want her to die alone. Basically, filling in a time between when family members would get there... So I walked in and sat down with this woman, she woke up and she took my hand and smiled at me, she didn’t say a word to me, she didn’t care who I was. She probably couldn’t read my badge, she’d never seen me before, she was just happy to have some human contact there. And that’s all that was, like at that moment, our politics, our religion, our, all these other things that we go about and what separates people, they had all left. This was a woman who wanted some human contact, and I was there, and that was like the greatest pleasure.

Like true listening, I did not observe much of a focus on sitting with a patient at Marina Hospice. It was discussed during the volunteer training a little bit but there was little focus. In observing one nurse I saw her tend to one unconscious patient and one demented patient, and in neither case did she sit with them, hold their hand and just be with them. Rather, she focused on taking vital signs of the unconscious patient and trying

to have a conversation with a demented patient. At Marina Hospice the focus for dealing with patient emotions is not from human contact but from strategies from the healthcare system, including adjunctive therapies, which Hospice on the Farm also used, and medications. At Marina Hospice a supervisor educated the volunteer trainees of what is done,

We'll use massage. That is a very effective agent or adjunct to help people... take their mind off their discomfort. A lot of people really benefit a lot from massage, and even family members have benefited a lot from massage from volunteers. We do relaxation techniques, if the patient wants, and some visual imagery. Sometimes we met with them, practicing aromatherapy, is that something that the patient particularly wants.

These adjunct therapies are used to help calm patients' anxieties and alleviate fears. In my exit interview with the volunteer coordinator at Hospice on the Farm she told me about someone else who had just passed the volunteer training and is a harp player, "They were called in this morning to talk about that and how she tried to match the breathing with her harp playing, the response of the family, and everything. It was just wonderful." Massage, Reiki and music therapy is also used to address matters of the body. One social worker at Hospice on the Farm advocated for the inclusion of alternative therapies, saying, "There's a whole protocol for pharmacological management of symptoms, [and] that's good. But when it's exclusively addressed pharmacologically, I have a problem with that. I would like to see at least adjunct things, like relaxation, or Reiki, or massage, or whatever." One of my patients, an 84-year-old man with Parkinson's disease, had pain and limited use of his hand, and he said in an interview,

“One gal gives excellent massages. She’ll spend an hour and a half massaging this hand so I can use, I can hold something.”

Effective pain control can bring a sense of emotional relief to a patient, so palliative drugs also address matters of emotions. Sometimes psychiatric medications are used to treat anxiety and depression. I didn’t observe this at Hospice on the Farm, but a consulting psychiatrist addressed the volunteer training at Marina Hospice and discussed treating depression,

Depression magnifies any other pain that you have. So one of the fundamental symptoms of depression is multiple aches and pain: backache, neck ache... every single joint aches, you get out of bed and you feel like you haven’t slept, and you feel like you’re 110 years old and you’re not. That’s because depression magnifies that pain.... So we can say to [the patient] “one of the parts of our treatment plan for pain control is to deal with the depression.”

The psychiatrist emphasized that treating depression should only be done if the condition lasts more than “a few weeks.” The same is true for the treatment of anxiety; usually a patient will feel some anxiety at the beginning of the diagnosis and then the feelings will decrease over time, but for patients who have a history of anxiety or remain anxious over several weeks, drugs to treat the anxiety could be indicated.

Hospice family members may feel some of the same emotions as dying patients—fear, anger, depression—and these emotions would be addressed the same way by hospice staff, with the probable exception of medications. At times in which hospice workers sit with a patient, they are often joining family members in their vigil. Family

members might also experience fear of their loved one's death and dying. Two other emotions of are specifically pertinent to family members: stress and grief.

Caregivers are often overwhelmed by responsibilities of being a caregiver. Before the patient dies, family members often experience stress dealing with the demands of everyday life and taking care of a terminally ill loved one. The volunteers at County and Marina Hospices offer practical and emotional support to families. While I was not in a position to directly observe this at Marina Hospice, the executive director explained the role of volunteers at the first training session,

Volunteers are offered too, and are available to the family, and to the patient, and some of you are volunteers. So you know, volunteers are available to do things like sit with the patient, spend time with the patient, spent time with the patient while the caregiver gets out of the house for a while, run errands occasionally.

This is some of the work I did at Hospice on the Farm. For example, one of the patients I had was married to a woman who was very active in volunteer work in the community and had many other interests such as yoga. This patient had several volunteers, three I knew personally and another three I had never met. While this is considered a lot of volunteers for one patient, the volunteers I knew, including me, really liked the man and his wife and loved being with him while she pursued her interests.

Perhaps the most pertinent emotional issue for the family is grief. After the patient dies Hospice on the Farm follows a routine to express emotional comfort. First, the hospice sends an African violet immediately after death. After 2-3 weeks a hospice social worker will call the bereaved to check on them as, according to a social worker, "both an invitation for us to come out and talk, just to, kind of hear the story on how it all went.

Give these people a chance to tell us what it was like, or it's just simply a 'we're thinking of you, you know, this is what we have to offer for the next year. Certainly take what you'd like of it.'" The hospice also sends handwritten notes at three months after the date of death, six months, the one year anniversary date, and at thirteen months. The three and six month notes say, according to a social worker that writes them, "We at hospice know that these months following loss are difficult. If you'd like to contact us, if you'd like to talk, here's our number. Here's what we do..." At the one year anniversary the note simply says, for example, "our hospice staff joins you in remembering your mom on this date." The thirteen month letter is, according to a social worker, "kind of a summing up... our involvement, saying that our formal involvement is over but that we'll always be available."

Hospices are mandated to have bereavement programs, though they can vary in size and scope. At Hospice on the Farm one aspect of the bereavement program is the bereavement volunteer. Bereavement volunteering was described by one volunteer,

Right now I'm doing a bereavement with a little lady who is ninety. It was her son who was the client, and he's deceased, and she has, she has lost both of her children, her husband, she has nobody. And I see her once a week and we do all sorts of things. You know, last week, we went and we got his stone because he was a veteran and we did that whole procedure. She still drives. A lot. [laughs]. I go grocery shopping with her, you know, we stock up. She can't carry all the bundles so we just stock up as much as we can, you know, for a week or two. But she does drive and she takes herself to various appointments in and around this area.

Much of this is not just emotional support for the survivor's grief, but practical support for living in the world. For example, many survivors have never had bank accounts, paid bills, or fixed their cars because their spouse always did so. This relationship is mediated by the hospice as well, according to a social worker

Our job is not to go out and replace the person who is gone, you know, it's to just help them find their way in the world and help them find other resources. But for some of these folks, if they never worked when the person was alive, they're incapable of coping and they're not going to become suddenly capable at the end of the year. So we are really, trying to build in more supports.

Both Hospice on the Farm and Marina Hospice offer bereavement groups to anyone in the community. Hospice on the Farm describes their bereavement groups as follows:

[T]hese groups are open to the community as well as to hospice patients. And over the years [other social worker] and I have developed, instead of doing a bereavement group for everybody we've broken them down into different kinds of losses. We run a group for people who have lost a spouse or a significant other in their life. We run groups for people who have lost adult parents. We run groups for kids who have lost parents, for adolescents, who have lost parents. And for parents who have lost children. Each of those are very different, and we have an eight week program for each group, which involves both education and support. They're really, really, positive experiences. I really gain so much from being part of them, because you just see people grow and heal in that time. Not get over it, not heal totally, but come to a place where they don't feel so alone, make relationships with other people.

While at Hospice on the Farm the bereavement program is run by the two social workers, there is a separate bereavement department at Marina Hospice. Marina Hospice

provides grief support for adults experiencing many different kinds of losses: adults who have lost a parent, men in grief, grief support for spouses and significant others, tragic losses such as suicide, accident and homicide, and parents who have lost a child. In addition they offer a support group for caregivers, a grief recovery seminar, and “presentation night” for information on how to adjust after a loss. There are also grief support groups for children and teenagers, organized by age. These support groups tend to be focused more on concrete activities, such as arts and crafts activities such as “memory boxes,” drawing pictures, and writing letters to the deceased. The volunteer training at Marina Hospice included a session on adult bereavement and another on children’s bereavement, and clients served on panels at each presentation to discuss their experiences with grief. One teenage girl described what the group did for her,

For me it was, I went to a personal therapist while I was in the group—that’s how I found out about it.... And so, it helped me because my personal therapy was, obviously, one-on-one with somebody who was older than me, and so the group was more people my own age, like teenagers and such....

It helped for me to see different points of view and how they grieve in some of the same ways and in different ways, and it kind of formed a friendship. Even though you only saw people once a week for eight weeks, I think it felt really safe in the group with them because they felt the same way you did.... It helped to know that I wasn’t the only one.

Once a year, both hospices offer a memorial service to families of those who died and I observed one at Marina Hospice. The memorial service consisted of an organist, a chaplain reading poetry and leading the bereaved in prayer, and the names of the deceased read. At the reading of the names, a family, individual, or group of people

would rise, come forward, and light a candle in remembrance of the deceased. These symbols—prayer, poetry, music, and candles—are meant to provide comfort to the bereaved

The Success of Hospice

For many, dying is a different experience than in the mid 20th century. Patients die at home more often, knowledge of the control of pain and other discomforts has increased, and patients often have emotional and spiritual support at the end of life. Much of the reason for this is the success of hospice. From the imagination of Cicely Saunders came a vision grounded in the expert knowledge of medicine, religion and social work, of a more compassionate way of working with the dying and their family members. However, the expertise of medicine, religion and social work was not enough. In order for hospice to succeed it had to compromise its mission with the Medicare Hospice Benefit. While the institutionalization of hospice allowed for it to reach more people, the economic and bureaucratic aspects of hospice, at times, overshadows the image of hospice as a social movement, where dying patients can come and meet their last days at peace, finding meaning in their lives, and relatively pain-free.

CHAPTER 6

BUREAUCRATIZED HOSPICE

The Compromised Social Movement and Frustrated Hospice Workers

For hospice to succeed it had to become institutionalized. Without support from medical and government institutions, hospice care would have been relegated to a fringe status within society. As a result of institutionalization, each hospice has wrestled with the principles of the social movement and the restrictions placed upon them by Medicare and other entities. This has been true for a long time, so it is not surprising that I found this in my study. What is new is how this struggle affects hospice workers on the emotional level. At Hospice on the Farm, the workers had a lot of difficulty accepting the rules and felt frustrated with the rules when they were required to compromise patient care. At Marina Hospice I found that hospice workers were not frustrated with the rules but were frustrated with uncooperative patients—patients who resisted the rules. The differing emotional responses are shaped by the cultural orientation of the hospices, particularly concerning how they define their work. While each recognized the social movement and bureaucratized culture, the hospice workers at Hospice on the Farm were more likely to see themselves as a part of a social movement that was going to change death and dying in the United States than those at Marina Hospice; therefore, they were more likely to be frustrated with the rules rather than frustrated with patients. At Marina hospice the hospice workers were less likely to see their work as part of a larger social movement. They were more accepting of the rules, therefore less accepting of patients who didn't want to play by the rules. In effect, the bureaucratized culture of hospice, to

differing extents, dampens the social movement culture, not only shaping the work but how the workers view their work.

The Economics of Hospice

One reason why the National Hospice and Palliative Care Organization can claim 1.3 million hospice patients in 2006 is because of the institutionalization of hospice. With its emphasis on delivering care at home, the hospice alternative to end-of-life care became a less expensive alternative to hospital care. In 1982-3 the National Hospice Study was launched by the Health Care Financing Administration, a study that showed that hospice home care was much more cost-effective than conventional hospital care. For example, during a patient's last year of life, hospice home care costs \$4001 less than conventional home care (Kidder 1988:56). This study led to the formation of the Medicare Hospice Benefit, which incorporated hospice into the health care system. However, as hospice care became institutionalized, many of the ideals that guided hospice care were compromised. Abel (1986) traces the path of hospice from a counter-institution to incorporation into the health care system. The Medicare Hospice Benefit imposed conditions under which a patient qualifies for hospice care, including the condition that hospitalization could not exceed 20% of patient days and that hospices are responsible for hospital stays. The Medicare regulations also directed what services had to be provided and under what conditions. Furthermore, in order to qualify for insurance reimbursement, many hospices had to be certified by the Joint Commission on the Accreditation of Hospitals (Later the Joint Commission on the Accreditation of Healthcare). The early hospice ideals—minimizing control by physicians, the use of an interdisciplinary team, an emphasis on human relationships and reduction of

professional/client dynamics, a reduction of expert/non-expert social distance, a recognition of death as a natural event rather than a failure, a challenge to the bureaucratization, institutionalization, and regimentation of medical care, and the emphasis on the family as a unit of care—became compromised as hospice became affiliated with established medical institutions in order to fulfill its mission. While hospice ideals had an effect on reforming the medical system, hospice itself became institutionalized and had become “a business” (Tehan 1985).

I found few differences between Hospice on the Farm and Marina Hospice pertaining to economic matters. Since Hospice on the Farm was affiliated with a large hospital they had more resources to draw on than Marina Hospice. However, I did not have access to the financial records at Hospice on the Farm. Marina Hospice posted their financial statements on the Internet, so I had more access. Marina Hospice’s bereavement program was mostly funded by community donations, and while Hospice on the Farm had a bereavement program, it was run by the two social workers who were already on staff working with dying patients; therefore I do not think their bereavement program was mostly funded by community donations.

Hospice on the Farm and Marina Hospice provide services for terminally ill patients regardless of ability to pay. However, hospice programs often claim that they don’t get enough money. Here’s how a social worker at Hospice on the Farm explained it to me:

SW: Now we’re losing money. I mean, the bottom line is we are spending more than we are taking in, especially with medications being the main reason, costs of medications.
JF: Costs of medications—now are they going up or—

SW: Mmm-hmmm.

JF: And the benefits are not going up?

SW: Right.

JF: So the insurance companies... they're paying like a fixed dollar amount and not, say if someone has to be on morphine—

SW: Right—

JF: You know, they're not saying "we'll pay for the morphine."

SW: Right.

By far, the majority of funds come from government and private insurance. The most money that comes to hospice is through insurance, including Medicare, Medicaid, Medi-Cal (at Marina Hospice) and private insurance. The hospice directors at each hospice explained their sources of funding at the first volunteer training. The director of Hospice on the Farm said,

In 1978 National Hospice Organization was formed, NHO, to lobby Medicare, or to lobby the congress, to pay for hospice. Because by 1978, we realized that we could not do everything without paid staff, that we couldn't recruit nurses, and social workers and pastoral care and provide all the services we need without someone paying for it. So we did lobby Medicare, and we did get hospice Medicare legislation passed in 1983, which was quite a feat because no other type of care has ever done that before or have since done that.

And the director of Marina Hospice said,

Well the good news is that in the '80s hospice became a Medicare benefit. So for anyone that is 65 or older, there is a Medicare benefit that covers hospice care. That's also true for Medi-Cal. So both Medicare patients were 65 and older, and Medi-Cal patients, they're covered by that. For folks who are younger or not Medi-Cal eligible, we have contracts with about 35 or 40 medical plans, medical care providers, Blue Cross, Blue Shield, etc. and they have hospice benefits in their coverage.... Let me just give you

an example. Medi-Cal and Medicare, they give us a per diem rate for every person that's in our care. Well, you kind of average that out and you look at it, and for some it covers the care but for some patients who need a higher level of acuity, need more expensive medications, need a whole lot more medical equipment, etc., it doesn't.

The vast majority of hospice funds come from some kind of insurance. According to Marina Hospice's annual report 2003-4, Medicare, Medi-Cal and private insurance made up 73% of their income. However, the 2001-2 Annual Report is more telling because it lists the dollar amount of income and expenses. Public and private insurance paid \$1,176,676, the cost of programs and services was \$1,587,263. Some of that deficit was made up in contributions, revenue from the second-hand store and other sources, but for the fiscal year Marina Hospice finished \$56,691 in the red.

Another source of revenue is contributions and fund-raising, such as golf tournaments. At Marina Hospice contributions were 12% of the total income. Many of the services Marina Hospice provides come from contributions, according to the hospice director:

And then we supplement with donations, we get from the community. Also our donations community cover bereavement care, both our children's program — 100% of our children's program — and the overwhelming majority of our adult bereavement programs is covered by donations. So, donations come from individuals, fund-raising events, places of faith, some of our local clubs, and the hospice thrift shop.²²

Finally, volunteers donate their time. Medicare regulations mandate that hospices must document that volunteers make up at least 5 percent of patient care hours and

²² The thrift shop later closed, due to lack of profit.

calculate the cost savings (“Hospice Matrix” 2006). At Marina Hospice in 2003-4, volunteers contributed 8,303 hours for a cost saving of \$142,728. Grants and an investment also supplement the Marina Hospice Budget.

Although these two hospices seem to be scrambling to make ends meet, the evidence suggests that hospice care still saves third-party payers money. In their public literature, Marina Hospice claims that studies show that hospice saves \$1.52 for every dollar spent on hospice Medicare claims and hospice patients save an average of \$2,727 in costs. The reasons why hospice care is less costly include: care is primarily delivered in the home, fewer and shorter stays in the hospital, a low level of technology, the family involvement in patient care, and bereavement support.

Bureaucratized Hospices

I observed a few differences pertaining to rules each hospice had to follow and they were minor. Both hospices had to follow Medicare regulations, and both hospices were certified by the Joint Commission on Accreditation of Healthcare (JCAHO). Marina Hospice had to follow rules particular to California, but I am unaware of state regulations that Hospice on the Farm had to follow. The main difference was that Hospice on the Farm was affiliated with a hospital that imposed rules on the hospice. Marina hospice, on the other hand, was a free-standing non-profit organization that had a board of directors.

Rules tend to govern 1) the conditions under which a patient can be cared for by the hospice, 2) the conditions under which the hospice can be licensed to operate, and 3) how patients should be cared for. The conditions under which patients can be cared for is shaped, mostly, by the Medicare Hospice Benefit. Once a person is determined by a

physician to have six months or less to live, they qualify for the first 90 days of hospice care. However, qualifications do not stop there. In order to qualify for another 90 days the patient must show signs of decline—in other words, the patient must continue in their process of dying—and must show it—in order to be recertified for hospice care. After the second 90 days, the patient needs to be recertified again every 60 days. For example, Hospice on the Farm has worksheets for determining prognoses for many common terminal illnesses and they show certain symptoms that must be present. In addition, the nurses who take this information must construct a narrative of the history and progression of the illness, showing that the patient is dying. Finally, and most important, the physician must answer “Why there is a life expectancy of six months or less.” As long as a physician can certify that a patient has a diagnosis of six months or less to live the patient can remain on hospice (Murphy 2006).

The Medicare Hospice Benefit is a source of frustration. First, because Medicare pays a per diem amount per patient and does not cover the entire cost of patient care, the hospice must pay for the rest, usually through fundraising. Second, Medicare mandates services without funding them, such as bereavement services. Third, the Medicare regulations that determine patient eligibility apply to all patients, no matter the payer source.²³ Finally, Medicare will only pay for patient services related to the patient’s

²³ It seems counter-intuitive that Medicare regulations would apply to non-Medicare patients. However, this is the case because hospices are not just reimbursed by Medicare but they join a Medicare program. In order to participate in the Medicare reimbursement program, hospices must abide by “Conditions of Participation” that “apply to a hospice as an entity as well as to the services furnished to each individual under hospice care” (Department of Health and Human Services, Centers for Medicare & Medicaid Services 2008: 32088).

terminal illness.²⁴ The clinical supervisor at Hospice on the Farm had a criticism of what Medicare will pay for and what it will not,

I do find frustrating about hospice as it stands right now, is that, the way the Medicare guidelines are set up, and the whole idea of something being related to the terminal diagnosis and not related to the terminal diagnosis—I often have problems with that, because we are one body. So, I mean... if you have heart disease, if you've had heart disease in the past ten years, and now you have lung cancer, or gastric cancer or liver cancer, and you're on hospice for your liver cancer, anything related to your heart we don't take care of. It's not related to your terminal diagnosis. It doesn't mean that the nurse doesn't listen to your heart or monitor your medications, but we're not paying, or responsible for that part of your care, then you can have a heart attack and go to the hospital and be treated, but if you want to go to the hospital because of your liver cancer, you know, you either have to have hospice pay for it or come off hospice or whatever. And that can create some real sticky ethical dilemmas... I mean we're a whole body. What's happening in one part of our body is affecting another part of our body. So that's difficult.

There are also regulations that control the ways in which health care facilities operate, and on the federal level that governing body is JCAHO, which is responsible for the certification of healthcare organizations and quality of care. Not every hospice is JCAHO certified, but probably most medical-affiliated hospices are. The certification process for hospices is time consuming and costly, but they have the advantage of earning the “gold seal” of approval. Hospices generally fall under the heading of home health, and JCAHO regulations are categorized as “patient functions” (such as: ethics,

²⁴ I am grateful to Margaret Murphy, Assistant Director of the Hospice and Palliative Care Federation of Massachusetts, for confirming these claims for me.

rights and responsibilities; provision of care, treatment and services; medication management; and surveillance, protection and control of infection) and “organization functions” (such as improving organization performance; leadership; environmental safety and equipment management; management of human resources; and management of information) (“Joint Commission Resources,” Home Care 2006).

JCAHO certifies hospices every three years. In 2002 JCAHO recertified Hospice on the Farm, and that caused a certain amount of stress in the hospice office. When I was informed of this by the volunteer coordinator I mentioned that I might come by and observe the process (which I didn’t), she said “make sure you wear your badge,” and the person serving as the principal investigator of this part of this study called me for my research protocol. In 2005 Marina Hospice was certified, and a copy of the “quality report” is available on-line. JCAHO evaluated Marina Hospice in terms of its 2005 patient safety goals and found that it passed. As the director said,

We are accredited through JCAHO. And we had been accredited for number of years, but we went back to be reaccredited, and it was a lot of preparation in getting ready, and in February, the auditors came, and they did their little barn and pony show, and the good news is we passed with flying colors, so we’re reaccredited and everybody’s happy, so now we can relax a little bit, but not a lot.

Sometimes states add policies not covered by the federal government. For example, under California Standards of Quality Hospice Care, hospices must have administrative policies that cover nondiscrimination, charges for care, causes for termination of services, meeting patients’ needs, the discharge of patients, record keeping, the dispensing and disposal of medications, program evaluation, protection from

infectious disease, personnel, compliance with the Patient Self-Determination Act, and disasters (“Hospice Matrix” 2006). In other cases states may expand upon federal regulations. For example, while the Medicare Hospice Benefit mandates “spiritual counseling,” California mandates that part of spiritual services include “assistance with memorial/funeral planning” (“Hospice Matrix” 2006).

Medicare regulations mandate that hospices as institutions have their own governing body. Marina Hospice is a nonprofit organization that has a board of directors that make policy. In the hospice office are two very large binders of policies set forth by the board of directors in the areas of

- Ethics
- Provision of Care, Treatment and Services—Assessment, Reporting
- Medication Management
- Provision of Care, Treatment and Services—Safety, patient ed.
- Provision of care, Treatment and Services—Intake and Admission.
- Improving organizational performance.
- Leadership
- Environmental Safety and Equipment management.
- Management of human resources
- Management of Information.
- Surveillance, Prevention, and Control of Infection

On the other hand, Hospice on the Farm is affiliated with a major hospital. That hospital has its own rules to which Hospice on the Farm is subject. For example, Marina Hospice orders its medications from a local pharmacist who comes to interdisciplinary team meetings and works with the hospice in providing appropriate medications for the best price. On the other hand, Hospice on the Farm must use the prescription drug

formulary that the hospital uses. One of the social workers, however, told me that she had a problem with it:

We used to just pay for medications that doctors would order. And granted it was a very wasteful system. You know, they would order a thirty day supply for a patient who had three days left to live. There were lots of dumping of narcotics and other expensive medications down the toilet,²⁵ and it was replaced by this [formulary], and they kind of manage, like an HMO prescription drug management.... The problem I have with it is someone that has been on certain medications prior to all these other ones and they don't work, if it's not in the ... formulary we can't favor it. So that makes me unhappy, and patients unhappy.

Of all the sources of rules, Medicare trumps them all. When JCAHO, state agencies and affiliated hospitals add on the rules become enormous. This can be frustrating for hospice workers.

Emotions and Orientations toward Dying

Hospice workers experience frustration. Some of frustration is day-to-day work frustration, such as when pain medication is becoming less effective or a co-worker is seen as not doing their job properly. One source of frustration is particularly interesting because Hospice on the Farm and Marina Hospice have differing responses, which is specific to the cultural orientation of each. At Hospice on the Farm the workers become frustrated with the rules; the culturally appropriate target of that frustration is the rules that prohibit the workers from performing the care they want. At Marina Hospice the

²⁵ After a patient dies, the hospice nurse who goes to the home is required to flush the remaining medications down the toilet, so the social worker is speaking literally.

workers become frustrated not with the rules but with patients and families who do not want to cooperate with the rules.

At Hospice on the Farm I observed a hospice worker express frustration about a patient only once, while I was observing a social worker's day at work. This was a patient, according to the social worker, who didn't trust the medical system because her daughter, according to the patient, died of misdiagnosed cancer. The social worker once went out of her way to bring a shower chair to the patient, but the patient didn't want it. I asked the social worker how often she gets difficult patients, and she said it was about as often as one gets difficult people outside of hospice.

Most of the frustration at Hospice on the Farm stemmed from frustration with the regulations. During my study of Hospice on the Farm the Health Insurance Portability and Accountability Act (HIPAA) had been passed but not yet implemented. In an interview the executive director expressed what she didn't like about her job,

I hate the regulation. There is more regulation every single year. Every time you turn around the government is giving us more hoops to go through, so that now we have two full time people who just deal with the regulations, and we used to have those people deal with patients.... It diverts resources, and it's foolish. It doesn't serve a purpose of improving quality or improving outcomes.... HIPPA Will add at least one full-time equivalent position to meet that regulation, coming out of the limited amount of money we already have. And I don't know that it's going to do any good. It's about protecting health records, which is a good thing. But I think we could achieve that without five hundred and eighty some tpages of regulation.

The main source of frustration for the workers at Hospice on the Farm is the Medicare recertification regulations, as explained by this social worker,

I think what has happened over the years, due to Medicare regulations, is that hospice had these criteria around how long it is for a person coming on the program before they die. So I really find that very difficult.... [I]f a person is on the program and has an illness that is not—does not have a projectile of dying, like cancer, where you move along in your progress pretty much in the same way. CHF [Congestive Heart Failure], Alzheimer's, COPD [Chronic Obstructive Pulmonary Disease], or people who have AIDS... don't have that kind of linear projection. So that they make it on the program when they're really ill but then get better with all the attention and support, and then we have to sign them off because they are not dying... in the time period that's specified. We don't have a cut-off at six months, but we do have a sense that if someone isn't, isn't hospice appropriate, isn't showing signs of decline, then they can't be on the program.

Two of the four clients I worked with were signed off of hospice before they died. One, a woman with COPD, was signed off because she needed to go to a nursing facility, and in her case the Medicare Hospice Benefit would not pay for both nursing home care and hospice. The second was a man with Parkinson's disease, who was signed off of hospice three days before he died. In my field notes I expressed my frustration that my patient was signed off of hospice and died soon after,

I found out from my volunteer coordinator why my hospice patient was about to be signed off of hospice.... [T]hree days before he died the social workers went there and said they couldn't chart a decline. He was going to the dentist and things like that, and in order to stay on hospice you have to consistently show signs of declining. Well, what I have to say is that he sure did decline. He showed us. The volunteer coordinator said that that's not the first time that happened. That happens quite a bit. So what's the logic of this? It seems like these rules are meant to put everybody into this kind of a dying trajectory, or a progression of

decline or something in the physical sense, and that's not good..... I will include this in my dissertation.²⁶

I was not the only one who felt frustration at a patient being signed off of hospice.

A clinical supervisor also expressed this during an interview,

I think it's stressful when we have to graduate somebody from hospice as well. The whole team feels edgy. Nobody wants to bring it up. So-and-so's put on weight, they are eating more, they are better, they're happier, they love hospice! So happy you take what is giving them quality of life. Then take it from them? That's really awful. That's a stressor.

At Marina Hospice there is also some frustration with the regulations. A social worker told me that most of the nurses there wished they wouldn't have to recertify patients as often as they do. A nurse also expressed this to me in an interview:

You have to write these monthly notes for medicine, giving updates to the doctor, and then you have to write, for every time they need to be recertified, you have to write another update for that, and it seems like every time you got to your mailbox, here's another few updates. So those are annoying. I wish we didn't have to do those.

But what is being expressed here is a frustration with the amount of paperwork, not with patients not being recertified. At Marina Hospice, patients are expected to cooperate with the hospice and when they do not the workers become frustrated. For example, there was a case of a man who was in a board and care facility and had been a hospice patient for about a year. The hospice nurse had a difficult time documenting a decline so was looking to decertify him as a hospice patient. Reportedly, the man's wife

²⁶ At the time, admittedly, I wanted to include this out of moral outrage. As I look back I still find it pertinent to the argument at hand and my frustration with the regulations is shown clearly here, so moral outrage aside the data warrants inclusion.

and the owner of the board and care protested and wanted to have a meeting with the nurse and social worker. Before the meeting (which I was not allowed to observe) the social worker said to the nurse “I don’t want this to be contentious,” and each of them vented their frustration of dealing with the family in an employee common area. The nurse had been treating the man’s bedsores, but the wife credited a new mattress for treating the bedsores. “Of course, I didn’t do anything,” the nurse said sarcastically.

After the meeting the social worker and nurse were joined by another nurse, the volunteer coordinator and a volunteer for lunch, and at that point the social worker and nurse vented about the contentious meeting. From what was discussed, the wife and board and care manager were trying to convince the nurse and social worker that the man should not be signed off of hospice and provided evidence that the nurse disputed. I was taken aback by this conversation because I could not fathom it happening at Hospice on the Farm. I actually sympathized with the woman because it seemed to me that she was just trying to get the best care possible for her husband, and I could understand that. When I vocalized that view, one of the nurses informed me that “*they* have to understand that *we* have our rules that *we* need to follow.”

The venting in this case followed to the interdisciplinary team meeting the next week, during which the nurse the previous meeting with the wife and the owner of the board and care, and at this meeting the nurse said out-loud “I just wanted to smack her.” While the nurse and social worker informed me that cases like these are rare, venting frustrations in the office is not. I observed others venting frustrations about “irresponsible” family during team meetings and informally in the office. As the nurse told me in an interview, “Here we talk a lot.... We kind of sit and vent things and talk

about difficult patients that we've had to deal with.... We do a lot of that within the group and that's what keeps you going.”

A final source of frustration that I witnessed at Marina Hospice is competition from for-profit hospices. This is one area in which I observed a social movement cultural orientation at Marina Hospice. The hospice workers at Marina Hospice told me that the for-profit hospices provide inferior care. Marina Hospice had patients formerly with a for-profit hospice but then changed to Marina Hospice. However, patients from Marina Hospice do not change to a for-profit hospice. A supervisor said to me during an interview,

These for-profit hospices coming in, I think they give us a bad name, because the services they provide are poor.... They are stretched way too thin and are just looking for clients... They have one on-call nurse for the whole area [a very large metropolitan area].... [in one case] it took, after the social worker signed the paperwork in the hospital, three days for the nurse to show up at home to do the assessment. They are not able to offer volunteer services or home health aids out here either.... It makes me sad, because we all started out as grassroots and providing all of this stuff and now it's become a money-maker.

Inevitably, there will be conflicts between what patients need and the rules that govern patient care. Hospice workers, particularly nurses and social workers, become frustrated with the conflict between the rules and patients needs. However, the nurses and social workers at Hospice on the Farm and Marina Hospice attributed differing responsibilities for their sources of frustration. At Hospice on the Farm the nurses, social workers, volunteers, the volunteer coordinator, director and clinical supervisor were frustrated with the rules because they saw the rules as limiting their ability to provide

optimal care for patients. Medicare, with its criteria concerning patients' qualification for hospice services, frustrates hospice workers when a patient is signed off of hospice because they are not showing signs of decline. The medical institution frustrates hospice workers by their rules concerning who can do what job and what drugs can be prescribed.

At Marina Hospice the workers are not frustrated with the rules; rather, they are frustrated with uncooperative patients. While cooperative patients are a source of joy and meaning for the hospice workers, uncooperative patients are a source of frustration. The venting I witnessed at Marina Hospice never concerned Medicare or JCAHO regulations; rather, they concerned uncooperative patients and competition from a corporate hospice. While there was some frustration regarding the recertification of patients, the frustration was not because it could interfere with patient care but because it was an unnecessary amount of paperwork. In fact, one of the office workers I interviewed at Marina Hospice said there should be more paperwork in order to protect against fraud, saying "How do they know they're hospice... [and] I didn't make people up?" Also, during interdisciplinary team meetings and conversations in the office hospice workers commonly complained about family members they defined as "irresponsible" or "uncooperative." While one social worker at Hospice on the Farm expressed her frustration about dealing with a patient, I did not observe a climate in which hospice workers vented about patients.

It is important to note that at Marina Hospice I did not observe the chaplain and bereavement services staff vent frustration about patients or their families. Rather, they expressed sympathy toward the patient and the family, engaged in active listening, and emphasized human connection in dealing with grief and loss. I speculate that this is

because their services are subject to less scrutiny than that of the nurses and social workers. For example, while bereavement services are mandated, there is a lot of leeway for hospices in terms of how they provide those services. Nurses' work is much more regulated and scrutinized than chaplains and bereavement workers.

The reason workers at Hospice on the Farm direct their frustration toward the rules and regulations while those at Marina Hospice direct their frustration at uncooperative patients is because of a different orientation. The workers at Hospice on the Farm think of themselves as a part of a social movement, while those at Marina Hospice, with the exception of the chaplain and those in bereavement services, think of themselves as a part of the health care system. Consider the following statements: Each one was made by a nurse during a volunteer training at each hospice concerning visits to patients in the middle of the night. The nurse from Hospice on the Farm, who described her job as a "calling," conveyed the following:

We have nurses that are on call 24 hours a day and we encourage on this initial visit, "If there are any problems, if there are any concerns, if there are any questions even if it's 2 or 3 o'clock in the morning, don't hesitate to call. Don't stay up all night wondering about it. Because there's somebody, she may be asleep, but she will wake up and she will answer your questions, and if you need a visit, she will make a visit at that point. And she will arrive at the doorstep with a smile on her face also, and be glad to be there. That's what we do."

And this one from Marina Hospice,

I do... visits in the middle of the night, much to my dismay, so I do have to go out and make visits. There are times, you know, as a nurse, the visit is not needed, but the patient or the family feels like they need a visit so you go out.

The hospice workers at Hospice on the Farm also had a background in addressing problems in society. The director described herself as a “hospice dinosaur” who came to work in hospice care because, as a young nurse, she witnessed a woman die in the hospital, alone and in terrible pain, and her colleagues ran in and out of the room because they didn’t know what to do, so she felt like she needed to do something about the way dying people were treated in the hospital. A social worker became involved because it was related to her previous work around AIDS and homelessness. A clinical supervisor became involved stemming from her interest in being a midwife and found the connection between birth and death. Others became involved because they found death and dying meaningful, such as a former nursing home nurse who always enjoyed working with the hospice patients or a social worker who had a lot of personal experience with death—including her father when she was young—and witnessed hospice care for her father-in-law. Many of these people became involved in hospice because they wanted to change a condition in society or they had personal losses that they wanted to make meaningful. This is in contrast to the nurses and social workers at Marina Hospice. In my interviews and observations with the rest of the staff I did not get a sense that they saw their work as being a part of something larger—a social movement that is changing death and dying in the United States. For example, one nurses expressed her frustration with patients who think that because they have hospice they will have someone with them 24-hours a day. I said that I could see how some people would think that, given the history of hospice and some of the original ideas that hospice embraced. She didn’t say anything in response. Admittedly, I don’t know what she was thinking, but she among the rest of the nurses did not express much to me that indicated that they embraced the ideals of a social

movement, the one exception being the supervisor who expressed dissatisfaction with the for-profit hospice trend because it goes against the grassroots history of the hospice movement.

This is not to say that those who worked at Marina Hospice didn't care for their patients and families. They did. At Marina Hospice I observed caring people who loved their job in health care but were sometimes frustrated by uncooperative patients. At Hospice on the Farm I observed caring people who were working to change the way death and dying were treated in the United States and were frustrated by the institutional regulations that prevented them from realizing the hospice vision with each patient they treated. The point here is not that one hospice is a social movement and the other is bureaucratized; rather, both of them are a part of the hospice social movement and both of them are bureaucratized hospices. Hospice as a social movement is one way of thinking about hospice and has its own set of tools for doing so, and the bureaucratization of hospice is another way of thinking of hospice and has another set of tools for doing so. This dilemma is, most likely, manifested in different ways in other hospices but the dilemma itself, the extent to which hospices treat rules as an impediment to serving patients and treating patients as an impediment to meeting the demands of the rules, is endemic to hospices in the United States.

The Limits of Hospice Success

The following quote is attributed to Dame Cicely Saunders and is repeated in hospice literature across the United States, "You matter because you are you. You matter to the last moment of your life and we will do all we can not only to help you die

peacefully but to live until you die” (Brown 2006). This sentiment is compromised in hospice, not because they do not care but the money it takes to care for the dying comes with conditions. In my time as a volunteer at Hospice on the Farm I have seen the hospice abandon patients—but the hospice workers felt terrible when they had to do so. At Marina hospice I observed workers vent their frustrations regarding patients’ families when patients’ family members complained about the possibility of being abandoned.

All hospices in the United States have to compromise the original ideals of hospice if they hope to survive. How the workers in each hospice respond emotionally to compromising situations varies, from frustration regarding the rules to frustration regarding uncooperative patients. The more the workers identify as social movement activists the more they will be frustrated with the rules; the more the workers identify as health care workers the more they will be frustrated by uncooperative patients.

CHAPTER 7

PROFESSING GRIEF

The Occupational Jurisdiction of Funeral Directors and the Management of Stigma

I think it is just a fear of the unknown really. These people haven't even seen a dead person, let alone taken care of the corpse and that. I think it is just a fear of the unknown and that maybe I'm a creepy person.

-- Funeral Arranger at Family Funeral Home

Funeral directors, arrangers and embalmers routinely experience odd looks and strained reactions when they explain what they do. Because death and dying are hidden in most of contemporary life, dead bodies are not only unfamiliar to many people but “creepy.” For funeral directors, embalmers, and funeral arrangers, contact with dead bodies is an everyday experience. They experience little creepiness but they do often experience stigma (Goffman 1963). Dealing with that which is rarely mentioned and even more rarely seen in polite society, they (and their work) are often discredited and their identities spoiled. Unlike physicians, who fight against death and relieve suffering or hospice workers who tend the dying, funeral directors must deal with the physical remains, the corpses, of those already dead.²⁷ Not only is the removal, embalming, and other handling of the corpse physically “polluting,” but funeral directors are also reminders of the reality of death. Furthermore, the stigma attached to the funeral directors’ work is only made worse by frequent criticisms that they are out to take financial advantage of bereaved family members. Yet, as Cahill (1999) points out, the very stigmatization of funeral directors gives them a certain “occupational jurisdiction.”

²⁷ This is a stigma that has occurred throughout the world. For example, Thompson (1991) noted that in some societies like Japan and India, those who handle corpses are forbidden from touching the living.

Because they have custody of a corpse, they have control over what is done and how it is done.

On a collective level, funeral directors cope with stigma by claiming a professional status and emphasizing service to the public (Thompson 1991). Funeral directors find themselves in a conundrum as they stake their jurisdictional claims. According to Andrew Abbott (1988),

A jurisdictional claim made before the public is generally a claim for the legitimate control of a particular kind of work. This control means first and foremost a right to perform the work as professionals see fit. Along with the right to perform the work as it wishes, a profession normally also claims rights to exclude other workers as deemed necessary, to dominate public definitions of the tasks concerned, and indeed to impose professional definitions of the tasks on competing professions (60).

Funeral directors have a full jurisdictional claim when it comes to handling, embalming and disposing of the corpse. They have an exclusive right to carry out this work and their legitimacy is backed by legal codes, professional ethics and public opinion. Furthermore, funeral directors' rights over the corpse are safe from infringement from others. According to Cahill (1999:107), "With the exception of a few pesky burial societies, attempted incursions across the boundary surrounding their occupational jurisdiction are virtually unknown."²⁸ Cahill also correctly points out that establishing this jurisdictional boundary came at a cost, for it is this jurisdictional boundary—

²⁸ While I agree with Cahill that funeral directors have rather solid jurisdictional boundaries, I would not characterize burial (or funeral) societies as "pesky." As shown in the next chapter, they have had more effect on funeral directors' work than Cahill implies.

removing, embalming, and disposing of the corpse—that stigmatizes funeral directors. In order to upgrade their spoiled identity, funeral directors staked out another jurisdictional claim: grief.

As opposed to handling the dead, which addresses a collective problem of what to do with human corpses, grief can be considered a “personal problems jurisdiction” (Abbott 1988: 280). Of the work funeral directors do, attending to the grief of the bereaved is the most status enhancing, elevating the funeral directors to an equivalent of a minister or psychotherapist. In contrast, handling a dead body is considered distasteful and profiting from death unseemly. Because clergy and psychotherapists also tend to the grief of the bereaved, funeral directors’ jurisdictional claim over grief is a divided claim, in which a contest between professional groups is settled by the division of labor (Abbott 1988:73), but this settlement is tenuous. For example, funeral directors claim the funeral performance as their domain but clergy have an “advisory jurisdiction” (Cahill 1999) in which “one profession seeks a legitimate right to interpret, buffer, or partially modify actions another takes within its own jurisdiction.”²⁹ Psychotherapists claim grief therapy as their jurisdiction, but funeral directors, as we will see, often infringe upon psychotherapists domain. In any case, funeral directors’ jurisdictional claim of tending to the grief of the bereaved is an important adaptation to the stigma they experience from their full jurisdictional claim of handling, embalming and disposing of the corpse.³⁰

²⁹ To be clear, when it comes to the work of tending to the bereaved in general, this is a divided claim among funeral directors, psychotherapists and clergy. Regarding the specific work of staging the funeral performance, the clergy have an advisory claim.

³⁰ Abbott (1988) discusses two other types of jurisdictional claims that this paper will not address. A subordinated jurisdiction occurs when one profession is positioned under another in the division of labor, such as nursing under medicine. Intellectual jurisdictions occur when a profession’s ideas are the basis for other professions’ work, such as the intellectual reliance on psychologists by social workers.

Preparing one's beloved for burial, being present for the bereaved and offering counseling, and, most important, organizing and directing a ritual in which the dead are remembered and praised is compassionate, honorable, and maybe even noble. One way funeral directors validate their jurisdiction is through psychological studies. For example, funeral director and sociologist Vanderlyn R. Pine, in a contribution to the collection *Acute Grief and the Funeral* (Pine et al 1976)³¹ begins by citing a classic study by Erich Lindemann (1944), who studied 101 bereaved individuals, including relatives of members of the armed forces and bereaved survivors of the Coconut Grove Fire. Lindemann argues that elements of grief include “(1) somatic distress, (2), a preoccupation with the image of the deceased, (3) guilt, (4) hostile reactions, and (5) loss of patterns of conduct” (142). The loss of patterns of conduct is the element that funerals address. Pine emphasizes that the funeral is a way to restore patterns of conduct, “for it provides an opportunity to carry out some sort of meaningful, structured, social activity” (105). Another contributor to the collection, Rev. Paul E. Irion (1976), asserts that funerals serve the needs of survivors because they provide a context of social support, help the bereaved face the reality of death, facilitate open expressions of grief, and provide a conclusion to the life of the one who has died . In asserting that funerals shape the way the deceased are remembered, Irion cites Sigmund Freud's view of that necessity:

Reality passes its verdict—that the object no longer exists—upon each single one of the memories and hopes through which the libido was attached to the lost object,

³¹ This volume includes 48 contributors, including academics, medical doctors, directors and funeral directors. Pertinent contributions include former high-ranking members of the National Funeral Directors Association and the National Association of Colleges of Mortuary Science. Author and funeral director Thomas Lynch calls this collection “required reading for all those whose work brings them in contact with bereavement” (Lynch 1977:181).

and the ego, confronted as it were with the decision whether it will share this fate, is persuaded by the sum of its narcissistic satisfaction in being alive to sever its attachment to the nonexistent object (34).

Funeral directors, therefore, borrow the authority of psychology in framing the need for funerals,³² and in the process they claim jurisdiction over tending to the bereaved. While others have argued that funeral directors establish professional boundaries in order to counter stigma (Thompson 1999; Cahill 1996) or that tending to the grief of the living is one way to counter the “rhetorical siege” funeral directors are under (Cahill 1999:118), I show that the technical expertise of handling corpses intensifies stigma, therefore funeral directors engage in more intense efforts to claim expertise in managing grief to manage stigma. Specifically, funeral directors establish their professional jurisdictional claim in three particular aspects of their work:

1. Embalming and restoring the corpse to look as if the deceased were “resting in peace” so the bereaved may, in their viewing, take away a comforting though illusive “memory picture.” To arrive at a point where their status is elevated by their restoration projects, funeral directors and embalmers must engage in the dirty work of removing, handling and embalming the dead. But in the construction of the “memory picture,” funeral directors transform the handling of the corpse from a stigmatizing, contaminating act to one that has psychological meaning and therapeutic benefits for the bereaved.

³² There is much more research on the value of funerals, including the redefinition of the relationship to the deceased and the reduction of the disruptive effects of death (Blauner 1966), constructing a new relationship with the deceased (Kastenbaum 2001), the opportunity to attain closure (Aiken 1991), and the psychological necessity of some kind of grief work (Grainger 1998).

2. Informal counseling, by which they serve as a resource and a comforting presence for the bereaved. Critically, however, funeral directors act as grief counselors despite at least occasional opposition and laws that work against them, since grief counseling can be seen as impinging on other professions' jurisdictional claims, such as clinical social workers.
3. Most important, directing the funeral performance, a "resurrective practice" by which the bereaved, through the use of culturally-appropriate symbols, are restored a sense of self and patterns of conduct.

In the process, funeral directors attempt to remove the focus from the handling of a corpse to the assuagement of grief.

Transforming the Corpse

Abbott (1988) loosely defines professions as "somewhat exclusive groups of individuals applying abstract knowledge to particular cases" (318). This definition implies that a technical skill is being practiced, and in the case of funeral directors the skill would be knowledge of the body and how to embalm. In other professions, legitimacy is often claimed in the public arena because the public has some understanding of how the work is accomplished. But funeral directors have a special problem. Unlike most other professions, they have to hide their technical expertise from the public because it is discrediting and stigmatizing as well as empowering. What is shown to the public, then, is not the process of embalming but the result: the embalmed corpse. The embalmed corpse can be displayed front-and-center in the funeral ritual, but the areas in which funeral directors and embalmers practice their technical skill is hidden in the sanitized embalming room, where few are allowed to observe in California. The

viewing of the embalmed body is promoted by funeral directors as helpful in assuaging grief, but getting to that point is a process that much of the public finds unappealing, even grotesque.

The most stigmatizing aspect of being a funeral director is also the most distinctive. It is the handling of corpses. Corpses come in various conditions, depending on the age of the deceased, the manner of death, and the time in which the corpse was exposed to the elements. This is the “creepy” part of the job, but it is necessary work that takes a certain amount of sensitivity and skill. However, this is not a part of the job funeral directors promote; instead, it is the restoration of a corpse from a dead body to a “memory picture.” Herein lies a tension: in order to arrive at the point in which funeral directors are of service to the bereaved—the memory picture—they must engage in some dirty work. This process begins at removal, when the funeral home staff arrives to take the body to the funeral home. According to Pine (1974) it is the “professional responsibility” of the funeral director to transport the corpse properly,

The body is manipulated gently and appears to be treated reverently. The hands are placed carefully at the sides and the deceased is covered with a percale sheet. The straps to hold the body onto the stretcher are not belted into place with the same abruptness that is common with hospital removals. The stretcher cover the zipper is closed quietly. These precautions are an important part of the way the funeral director constructs his treatment of the dead even though such concern and professional treatment may go completely unnoticed by the family. To swing the body violently onto the stretcher, to yank the straps across the chest and legs, and then to bounce it downstairs probably would draw considerable attention.

Removing the body in such a way is more important than one might think. The removal is often the first in-person contact the funeral home has with the bereaved. It is imperative that the removal be done in a dignified, sensitive manner. One funeral director told me in an interview,

When we go in one of the hardest things is when you take a person from their home. It is the last time this person, this body will ever belong in that home.... So, when we do it, we wrap them up in sheet.... You know how you take a baby from the hospital you wrap them up really tight in that blanket? Well, I say that is exactly what we are going to do. We are going to wrap them up really tight in a sheet. We aren't going to cover their face, put their head on a pillow and we will take them out. If we see any people we will cover their face, but other than that, no we aren't going to cover it. No bags, we aren't going to put them in a bag.

At Family Funeral Home I made a removal with a staff member. In this situation I was going to interview a staff member when the removal call came in, and the funeral director suggested that I help with the removal, a 92-year-old man in a nursing home. When we arrived in the van we were met by two of the decedent's sons, one of whom spoke with us the most about making future arrangements, while the other, distraught, did not interact with us much. They chose to wait outside the room while we removed the corpse. The staff person informed me that the removal could have been done alone except there was a support beam by the bed so help was needed to get the deceased around the beam and onto a gurney. The staff person did most of the work, such as turning the corpse and wrapping it tightly in a sheet. In this case, the man's head was wrapped in a sheet, probably because we were in a nursing home. After this removal, the staff member, a funeral arranger and former apprentice, gave each of the sons a hug. I expressed condolences and shook their hands.

Family Funeral Home emphasizes “caring” as an appeal in their marketing. It is not considered inappropriate to hug a bereaved family member or otherwise show caring. The skill in a successful removal lies in sensitivity to the bereaved, but not all are sensitive, as shown by this quote from a manager of a funeral home that specialized in cremations informed me of someone he thought was particularly insensitive,

He would go to families’ houses and he would have a box and a dolly... and he’d put the body in and go down the stairs, and one time the body tumbled out in front of the family. That guy was ruthless. I think he was one of the fly-by-nighters that never should have been allowed to be in the industry... The whole idea that you can do a removal using a dolly, like you were moving a refrigerator? That’s crazy!

Once in possession of the corpse, the funeral director’s task is to transform it, through embalming and restorative art,³³ to an image of someone who is “resting in peace” so the bereaved can view their loved one and later recall a comforting “memory picture.” This creation of a “memory picture” is thought to be healthy for the bereaved and contributes to recovery from loss. As Clarence Strub and L.G. Frederick (1989:52) point out in *The Principles and Practice of Embalming*,

Basically the embalmer is a creator of illusions—pleasant illusions which banish the traces of suffering and death and present the deceased in an appearance of normal, restful sleep.... We call this illusion a “memory picture” for it will create in the minds of the relatives and friends of the deceased a mental image which can be recalled to mind at will during the succeeding years.

³³ Although they are two separate processes, many people in the funeral industry think of embalming and restoring as so closely related that when one says “embalm” they also include the restoration work. Embalming, then has two meanings: one is the preservation of the human remains and the other is the entire process by which a corpse is transformed to a suitable viewing.

To get to the illusion the embalmer must face reality. While funeral directors discuss the importance of viewing the illusionary embalmed corpse to face the reality of death, the technical skills employed cannot be used to justify their professional status. One of the most detailed, technical descriptions of the embalming process I have read comes from Green's (2008) anthropological study of death and dying (74-75):

The corpse is undressed, jewelry removed and inventoried, and the body laid out for washing on a stainless steel or porcelain table, the head slightly elevated and hands and arms resting at the sides. Messaging [sic] and flexing remove rigor mortis, giving the corpse a more relaxed look. Two procedures are involved, beginning with arterial embalming. A cut is made on the lower neck to access the carotid artery and jugular vein, and a tube is inserted into each. The one in the artery is attached to a pump and tank of embalming fluid, the other drains blood as it is forced out. Pump pressure is kept low, steady and is closely monitored since blood clots can form blockages, back up fluid, deprive some areas of preservative, and (even worse) puff up the face so it requires remedial work later. Dyes are added to the preservative to adjust skin color but that is tricky since they can interact unexpectedly with medicines still in the body, creating unwanted coloration effects....

After draining, cavity embalming begins. A cut is made just above the navel and a trocar inserted. A trocar is a sharp, pyramidal-shaped blade at the end of a metal suction tube about eighteen inches long that is used to "aspirate" (the technical term) the organs of the gut and chest. That means vigorous puncturing and slicing so that fluids and gas trapped in intestines, the stomach, bladder, lungs, and adjacent organs can be suctioned out. Then full-strength embalming fluid is pumped in. If during this procedure the chest collapses, it is stuffed with packing material until it returns to its original appearance. The anus and vagina are packed as well so that fluids will not leak out.

The deeper one probes into the body, the dirtier the work becomes. Washing the body brings one into close contact with death but the contact is skin deep. Arterial embalming exposes one to blood, which is dirtier than skin contact, but suctioning the internal organs with a trocar and packing the anus and vagina might be the dirtiest work of all. This is all in pursuit of cleaning up the corpse for presentation to the family and other mourners. In a natural death, the blood drains to the lower part of the body, therefore the surface capillaries that contribute to skin coloring are lost. This gives a dead body a sort of a pale look. The mouth and eyes are also wide open. If there has been an autopsy there might be further problems, particularly the detachment of the top of the skull in the removing of the brain (Pine 1974). Many Americans do not wish to see their loved one in such a repulsive state (Leming and Dickerson 2007), therefore the corpse is “restored” to look as if the deceased is “resting in peace.” Restorative art can be categorized into four “codes.” First, *codes of posed features* is the closing of the mouth and eyes and other poses to mimic the appearance of sleep. Second, *the cosmetic code* cosmetics are applied to the face and the hair is arranged to look natural, and again giving off an appearance of sleep. Third, *clothing codes* are generally the deceased own clothing, usually a suit or light-colored dress, and most often long-sleeved with a high collar. Often what is suggested is an outfit the deceased wore to a wedding or another special occasion. Finally, *codes of positions* refer to positioning of the body in the casket (Barley 1983).

Because of California law I was not allowed to observe an embalming. Immediate family members are legally allowed to observe (Cemetery and Funeral Bureau), but I did not know of any family members who wished to observe. Because of the amount of blood

present and other things, embalming is “shrouded in secrecy” (Pine 1974). I have seen embalmed bodies and these codes seem accurate. The bodies did look like they were peacefully sleeping, with the mouth and eyes closed and make-up that resembled natural skin color. Most were dressed in suits or dresses (though people usually do not sleep in their best clothes) and positioned in the casket to look like they were resting. The most obvious sign that they were dead was the lack of breathing. This illusion is what is promoted by funeral directors to attain professional status.

Generally, funeral directors, embalmers and funeral arrangers in my study believed in viewing the body as a way to assuage grief. The mortuary science instructor explained why the memory picture is important:

They can see Mom, not with all the tubes in her and not with all the I.V. lines, or Dad was laying on the side of the road the last time we saw him, with blood all over and his head that cracked or something like that. And we can restore that to a memory picture that is more pleasant.

At Family Funeral Home the family is not only invited to view but sometimes participate in dressing the body or having a more meaningful interaction with the deceased than viewing. For example, one funeral director told me the story of another funeral director at the same funeral home that,

brought in his lawn furniture and put the girl on the ground on the lawn furniture and Mom lay down next to her daughter. Just lay down with her... This was a little girl who had been out in the woods, and had been there for a while, so there were things that were not good about her, but she had been embalmed, they [another funeral home out of state] did a beautiful job.... And I thought that was wonderful.

A funeral arranger also discussed the importance of viewing, based on personal experience,

When I was 17 my step-brother, who was my best friend, who was 16, committed suicide. He got involved with drugs and hung himself. He was found and identifying marks, tattoos he had and stuff. I never saw him, my mother said, "Oh no, that would be too hard." And to this day I regret that I didn't see my brother and kiss him goodbye and know that it is really him. Because in my head, for years, now I know he is really gone, but for years in my head I just thought, "Well anybody could have got that eagle tattoo with the ribbon around it." I just had myself convinced for a long time that it wasn't really him because I didn't see him. ... At the time it didn't bother me as much as over time. Thinking about it, it got worse instead of better, not seeing him. I think it is really important for people to have that closure.

Restoring a corpse is an art form, though it may not seem like it from a lay perspective. One embalmer liked to show me the work she had done on a corpse, describing what the corpse appeared like when it arrived and after restoration. Another embalmer claimed the ability to tell who restored what body at her funeral home and showed me a restoration job of a colleague who "just doesn't have it":

I can tell by the colors of the lips and the makeup job. I embalmed this gentleman but the other embalmer dressed him in I can tell so many things. The sleeve should be like this, you shouldn't see that sleeve. That's like underwear, shouldn't even be showing. The pillow's not around... This is bad. The makeup job is awful... dressed like this doesn't even cover his shoe.... He's been doing it for twenty years, no matter how many times he does it he never gets better.

As this was described to me I could not tell that it was a bad restoration job, but this example shows that there are standards of work among these professionals that the

uninitiated would not notice. The uninitiated is also often unaware of the embalming process. In fact, in one of my interviews with a funeral director, I asked him to describe the embalming process but he said nothing about cavity embalming, and I do not remember any of my informants or respondents using the term “trocar.” At other times, when the decedent died a physically traumatic death or the corpse has decomposed beyond the point in which embalming can occur, those close to the deceased are discouraged from viewing. One funeral director discussed the challenges of decomposition if the decedent

has been left to the elements and is found a week after death, now you’re probably looking at a different situation and clearly decomposition would have fully set in by then and embalming would be challenging, in fact, to the extent that depending on certain circumstances, I would say it may be almost impossible to make that person viewable in what we would consider a conventional sense.

Another funeral director discussed the challenges surrounding trauma,

There are certain things you can and cannot do to make somebody have a natural appearance, so a lot of times it’s difficult when the families insist on having a some type of a viewing, and it’s up to the funeral director or the person making the arrangements to come to you as an embalmer and ask your opinion, “do you think this person could be prepared for viewing without adding any additional stress or trauma to the family?”

But even with trauma or decomposition, other funeral directors try to accommodate some sort of nontraditional viewing, even if it is only a hand that shows because the head has been crushed. The extent to which some funeral directors will go to accommodate a viewing show how important they think it is in addressing grief. One funeral director related this experience from his family,

I had an uncle who had passed away, and he hadn't been home for quite a while, he was out of the state, and my grandmother had told me that, because of the circumstances of his death, she couldn't view his body. He was found several weeks after he passed away, so his body was beyond being able to be prepared for a viewing. And she had said that, even years later, there was that occasional time when someone would knock on the door or the phone would ring and her mind would think "maybe that's him".... Even though she knew it wasn't, she still had that because she didn't see him physically. There was a casket there, but in her mind, maybe that's not her son. So this was related to me long before I even thought about the funeral business.

In the tension between the process of removal and embalming of the corpse to the viewing of the illusive memory picture, the funeral director's expertise lies in helping the bereaved face the reality that their loved one *has died* while shielding them from the reality of *death*. However, in order to gain professional legitimacy in the eyes of the public, funeral directors must mask the process by which they create the illusion—thus their technical skills—to cover their stigmatized work and publicly present the illusive result of their work; an embalmed corpse, resting in peace, comforting the bereaved so they can recall a beautiful memory picture.

Informal Grief Counseling

Funeral directors' jurisdictional claim over embalming is not contested. The same is not true of grief counseling. Clinical psychologist J. William Worden (2009) defines grief counseling as "helping people facilitate uncomplicated, or normal, grief to a healthy adaptation to the tasks of mourning within a reasonable time frame" (83), is in contention. Worden asserts in his fourth edition of *Grief Counseling and Grief Therapy* that "I said in the first edition of this book 25 years ago that I don't believe that we need

to establish a new profession of grief counselors. I still believe this.” He continues by quoting a social worker, D.M. Reilly, who states that “We do need more thought, sensitivity, and activity concerning this issue on the part of existing professional groups, that is, clergy, funeral directors, family therapists, nurses, social workers, and physicians.” Implicitly, Worden and Reilly promote a divided claim to grief counseling, in which several professions that work with the bereaved can engage in grief counseling. Furthermore, the American Academy of Grief Counseling, a part of the American Institute of Health Care Professionals offers “Certification and Fellowship Programs for qualified professionals including, physicians, nurses, counselors, social workers, funeral directors, clergy, and other professional providers practicing the specialty of Grief Counseling” (American Academy of Grief Counseling 2009). However, despite the endorsement from other professionals, there are impediments to funeral directors claiming grief counseling as a jurisdiction, not the least of which is California law. The California Business and Professions Code, Section 4996(b), states that “It is unlawful for any persons to engage in the practice of clinical social work unless at the time of so doing such person holds a valid, unexpired, and unrevoked license under this article,” and section 4996.9 defines clinical social work as “a service in which a special knowledge of social sources, human capabilities, and the part that unconscious motivation plays in determining behavior, is directed at helping people to achieve more adequate, satisfying, and productive social adjustments” (Legislative Council, State of California 2009). So while other professionals and professions might welcome funeral directors as grief counselors as a divided claim, in California the law is stated so that if funeral directors

engaged in grief counseling they could be practicing clinical social work without a license.

Nonetheless, many funeral directors across the United States practice grief counseling. In a survey of funeral directors, Bradfield and Myers (1982) found that 82 percent of them talk to the family about the deceased concerning non-funeral matters. In addition, articles in many of the funeral industry publications promote grief counseling. For example, in an article by B. Bates and Ron Hast (cited in Bradfield and Myers 1982:132), “I believe that counseling, that helping human beings work with their feelings, that talking with people in such a way that the funeral becomes a more therapeutic experience... that’s what our future’s about.” In addition, Vanderlyn Pine (1974) states that funeral directors do not practice therapy in the traditional sense but “consists of advice concerning funerary practices, the creation of a suitable atmosphere for bereavement, and the providing of counseling service aimed at helping the bereaved to understand loss through death” (142).

Many of the funeral directors and arrangers I studied still tried to serve the needs of the bereaved in spite of the law. One legitimate way to do so was referrals. An embalmer and funeral arranger that I interviewed also discussed the importance of advising survivors to utilize available resources, but to do so carefully:

Give them resources that are available. Sure we provide grief counseling or group therapy at the VNA Hospice—it’s actually... by the VNA Hospice.... I’m not a psychologist or psychiatrist. The resources that they have, their family, their clergy people, hospice, their doctors, but I have to be very careful. I can’t say “You need to talk to a psychologist.”... How dare me. I would never say something like that. But I do suggest that they talk to someone, whether professional or personal.

In addition, the mortuary science program has a counseling class and a Psychology of Death and Dying class, which, according to the instructor, covers the basics such as the stages of grief and the tasks of mourning. One funeral director I interviewed informed me that while they cannot call what they do “grief counseling,” the tasks they carry out qualify as counseling:

Do we do counseling? I suppose we do. Legally we don't call it counseling, but I think a lot of funeral directors do a lot of counseling. None of us are licensed to do it, but if we are good at what we do and we've learned from our life experiences and working with the families, then hopefully it is helpful informational counseling, that [make] people feel good. Grief expressed is grief diminished, so if you are able to talk about it sometimes that is the funeral ritual itself, because they have chosen not to have a ceremony. So our little talking about this person's life becomes very healing in itself.

At Family Funeral Home counseling is not limited to talking to the bereaved about their feelings, but educating them and others about grief. For example, Family Funeral Home distributes an anonymous pamphlet titled “The Holiday Season and Grief: Helpful Ways for Those Who Grieve to Heal and Find Hope.” The pamphlet offers advice to those who grieve during the holiday season, which includes deciding on which activities to participate in, talking to others about choices, and framing the grief in meaningful ways, such as lighting candles in honor of the deceased or offering toasts to the deceased at holiday meals. The pamphlet also encourages engaging in volunteer work and other advice throughout the year to cope with grief, such as “join a support group” and “recording your thoughts.” Bible quotes and quotes from professionals are ubiquitous, and a section on suggested reading on grief ends the pamphlet.

Some of the grief counseling goes beyond the time before and immediately following the funeral. Another funeral director, who also works for the corporation Carriage Services, discussed the imperative of what he called “aftercare,”³⁴

Our services don’t end after the funeral. They go on if they have needs from us. We’re a resource in different areas. Aftercare is known in our profession.... Aftercare, following up, how they’re doing.... [Calling and saying] “How are you doing, Mrs. Smith? How are you holding up? It has to be tough, isn’t it?” These types of things, instead of [just] taking their money....

Funeral directors, then, engage in informal grief counseling. While some funeral directors have talked about claiming grief counseling as their jurisdiction, they do not formally claim this in California, not because there is a consensus among other professionals that protect the boundaries but California law implicitly forbids it. However, showing compassionate care and educating the bereaved about the grief they experience are ways in which the funeral director may counsel, and this probably often has a therapeutic effect, so some funeral directors practice grief counseling without naming it such.

The Funeral Performance

It is the funeral director’s job to ensure that the funeral ceremony goes smoothly. A funeral is a performance and the funeral director is not only the director but is in charge of the stage set, props, lighting, and audio-visual equipment. Making sure that everything works and tending to all of the little tasks is important so the funeral can go smoothly and those in attendance can be comforted and grief can be assuaged. As

³⁴ A similar practice, “The Continuing Care Program,” is offered by Service Corporation International (Kellar and O’Kane 1999). However, SCI has done a lot more in providing professional grief counseling, as shown in the next chapter.

opposed to psychotherapists, funeral directors provide a comforting ritual to those in attendance that shapes the memory of the deceased, provides a place for the expression and struggle with grief, and restores patterns of conduct. Also, while clergy are actors in the ritual performance, they do not attend to the backstage details as funeral directors do (Turner and Edgley 1976). Therefore, their jurisdictional claim is more of an “advisory jurisdiction,” (Cahill 1999) similar to their status in relation to medicine and psychiatry (Abbott 1988:75). In addition, a funeral is a “resurrective practice” that “restores a sense of basic security fractured by death” (Seale 1998:4). Seale explains,

The task of the living is to enclose and explain death, reduce its polluting effects, and symbolically to place individual deaths in a context which helps survivors turn away from death and towards continuing life (81).

To conduct a funeral that will serve the bereaved, then, is honorable work that funeral directors promote, in contrast to the dirtier work of handling and embalming the corpse.³⁵ There are many ways to remember, grieve, and move on from the loss of a loved one. Friends and acquaintances offer condolences, a family member or close friend might deliver a eulogy, or (as I observed) a minister might say “I bet she’s bowling 300 in heaven.” Comforting symbols are of most importance. The embalmed body, laid out in an open casket and looking as if they are resting in peace, becomes a comforting symbol, expressing the belief that their loved one is now at rest. In my observation of Family Funeral Home there are many symbols that are meant to comfort the survivors, both in the chapel and the mausoleum. One category can be called religious symbolism, such as Psalm 45, (“Yea, though I walk through the valley of the shadow of death, I will fear no

³⁵ From time to time, funeral directors will conduct a service, particularly if a family has no connection to clergy in the community and prefers a secular service, but the ones I spoke to would rather not because they need to tend to the backstage details during the service.

evil: for thou art with me; thy rod and thy staff they comfort me”), crosses, and the Christian flag. Hymns are also played to comfort the bereaved. One funeral I observed played religious songs such as “The Old Rugged Cross” by George Bennard (1913) and “In the Garden” by C. Austin Miles (1912).

Another category of comforting symbols concerns nature. Green (2008) refers to Seale (1998) in his analysis of children’s books on death and dying argues that “In telling tales, we verbally repair the broken world a death creates, reincorporating the dead by means of a tamed nature we can control and understand” (146). Turning towards tamed nature is a way of turning towards life, and as children’s books on death and dying are filled with images of tamed nature, funeral imagery is as well, and I observed this at Family Funeral Home. Flowers, trees, plants, birds, sunsets, and bodies of water are ubiquitous. Perhaps the epitome of nature being employed to comfort the bereaved in a resurrective practice I found at a niche in the mausoleum titled “Do Not Stand at My Grave and Weep,” by Mary Elizabeth Fyre:

Do not stand by my grave and weep;
I am not there, I do not sleep.
I am a thousand winds that blow,
I am a diamond glinting on snow.
I am the sunlight on ripened grain.
I am the gentle autumn rain.
When you awake in the morning hush,
I am the swift uplifting rush
of quiet birds encircling flight I
am the soft star shine at night.
Do not stand by grave and sigh;
I am not there I did not die.

The Chinese funerals I observed at City Mortuary also contained symbols meant to comfort, though the specific content of these symbols is different from that at Family

Funeral Home and, for me as a Westerner, difficult to interpret. For example, I observed many different styles of floral wreaths at the funerals, and did not find out until later that different styles have different meanings, depending upon the survivor's relationship to the deceased (Crowder 2002). Some of the symbols were explained to me by the funeral director. For example, the Chinese symbol of longevity was engraved on many caskets. As attendees at a Chinese funeral leave, candy is distributed, which as explained to me by the funeral director was meant to take the bitterness out of mourning. During the processional, paper with holes is scattered on the ground, which represents money and it is meant to distract the devil from the decedent. Finally, a coin placed between the lips of the decedent is meant to pay the toll to the underworld. Funeral directors are conscious of the culturally-appropriate comforting symbols they employ to assuage grief. For example, a funeral director at Family Funeral Home informed me that when they serve a Jehovah's Witness family they remove the Christian and American flags from the stage. When City Mortuary serves a traditional Chinese family they display Chinese symbolism at the front altar, but when they serve Catholic families the Catholic symbols are displayed.

The funeral performance as an accomplishment, but sometimes the funeral fails to accomplish what it sets out to do, both in terms of the script and the ensuing effect on the bereaved. For example, the names of decedent's family members are often read at funerals, but once a funeral director made a mistake:

I had a funeral service where I was responsible for typing what we call a clergy card, and it's a help for the minister to read the names [of surviving family members] off at the funeral. Well, I left the daughter off. Afterward, the daughter said "My name was not read there, Pastor. Why didn't you read my name?" "Oh, it wasn't on the card. I'm sorry I missed it." "Well, who left my name off?" She came

to me and said, “This made it sound like my father didn’t care about me, and I was very close to my father.” It was gut-wrenching. Simple, little mistake, but it had a huge effect on that daughter who was going through grief at that time.

If the inclusion of family members’ names represents closeness, family, and meaningful relationships, the omission of a name represents an omission from the family. This omission would make it difficult for the daughter’s sense of security to be restored. Mistakes can also loom large during the funeral procession.³⁶ The hearse, motorcycle escort, flowers and other symbols of comfort, is the responsibility of the funeral director. Like the funeral service, these processions are highly ceremonial, cannot be rehearsed, and mistakes are magnified. At City Mortuary I observed a few Chinese processions. At the end of the service those in attendance leave the chapel, with the family and funeral home attendants the last to leave. The casket is wheeled to the front door, where the hearse is waiting. The casket is loaded into the hearse as a marching band plays, usually “Amazing Grace.” The marching band leads a procession through the streets with a motorcycle escort ahead to direct traffic, followed by the hearse and a “picture car,” which is a black convertible showing a large framed picture of the deceased, followed by a limousine (which presumably has the family) and other cars, usually black. At some point along the way to the gravesite (which is in a nearby city but not very accessible by city streets) the marching band and picture car will drop from the procession.

Like the funeral, the skill in directing a procession is not obvious when things go right but becomes very evident when things go wrong. One funeral director discussed some of the events that are amusing when seen in retrospect but not amusing at the time,

³⁶ The term “funeral” comes from the Latin *Funeralis*, meaning “torchlight procession” (Habenstein and Lamers 1996).

It's pretty funny though, some of the stuff, when the hearse breaks down on the side of the road, a block from the cemetery and you get triple A [American Automobile Association] there, and all you have done is run out of gas. It is pretty funny.... Or when the battery goes dead and you go out and the other funeral director has ripped off the molding on one side of the car. So you parked in a certain way so that the family can't see that the molding has been ripped off earlier in the day and you forgot to turn the light off at the cemetery and so the battery is really weak and it goes bad. So then you are trying to jump it during the service, and it starts smoking. And it's pretty funny. You get these three women standing around, like with these stupid flowers, looking like "everything's fine, I'm just going to wait until you leave, and then we're going to leave, we're going to take care of everything. We are talking... like everything is just fine, when in fact it is not.

Here, the attempt to cover mistakes shows how funerals are an accomplished performance. Sometimes, mistakes can be so severe that they fail to cover the dirt that stigmatizes funeral directors, and the reality of death is far from comforting. One funeral arranger told me a story of what happened at a previous job,

FW: Here... the pallbearers only use the handles to carry the casket, but in New York they push it up on the shoulder and hold it like this, like the military. The one time when we walk outside of the church, someone slipped, okay. The casket flipped and hit the ground and the knot came out and the body rolled over.

JF: Right on the street.

FW: Yep.... The first thing we do, we have a mutual knowledge. I think we have over ten limos, so we have ten limousine drivers so we all surround it immediately and push the body back upside down. We don't have time to put it right back in. We push it, close it, push it to the church.

Both the funeral arranger and I had a good laugh about this situation, but the image of a dead body, not resting peacefully but falling out of a casket and onto the street, is not comforting but a polluting image, reminiscent of the stigma faced by funeral directors. Funeral directors elevate their status by directing a ritual, through the use of comforting symbols, that contain and explain death and provide direction for the bereaved. It is the funeral director's job to make sure that nothing interferes with the funeral service. When mistakes happen they often have symbolic meaning too, but those mistakes not only prevent the resurrective practice but contribute to the spoiled identity of funeral directors.

Grief as a Jurisdictional Claim and Managing Stigma

Handing the dead is stigmatizing, but funeral directors elevated their status and managed the stigma by claiming grief as a jurisdiction, framing their work as experts at tending to the grief of the bereaved. For this, they minimize the polluting aspects of death—and their part in that pollution—that threaten to spoil their professional identity. They hide their expertise in handling the corpse, and expertise in which they have full jurisdiction, but emphasize their expertise in comforting the bereaved, in which they have a divided claim. One way they comfort the bereaved is through transforming the corpse to a comforting memory picture that will, simultaneously, help the bereaved face the reality that their loved one has died without having to face the reality of death. While they can provide some sorts of informal counseling and education, they cannot claim that jurisdiction officially in California because the law protects other professional claims, such as clinical social workers. What they can do is direct the funeral performance, and accomplished activity that, through the use of comforting symbols, provides a way in

which death can be contained and the sense of self and patterns of behavior can be restored.

If funeral directors are able to assuage the grief of the bereaved they are appreciated. A funeral director at Family Funeral Home told me of something he received from the parents/grandparents of a daughter and granddaughter who were victims of a double homicide,

If you look in our hallway you would see a little plaque from the... family and it was their granddaughter and daughter. They were grateful to us for allowing them to view their family members before they were cremated without that gaping and to see them. I remember meeting with that family and just saying "I think what might help you is to see your daughter and granddaughter before they are cremated in a way that is not this horrible thing that you have been told had happened at the scene. Even though that happened we can at least give you an opportunity to physically say goodbye to them." Taking this horrible thing and letting the brother who survived the ordeal and the grandparents, the parents of the mother and the grandparents of the daughter to see them.

The plaque in the hallway is on display, not the embalming. Without expertise in assuaging the grief of the bereaved, funeral directors become like early 19th century undertaker: "In them, the preoccupation with the physical and gruesome side of death was apparent" (Habenstein and Lamers 1989:105). There are those who aim to strip the funeral directors of their expertise in embalming, grief counseling and funeral directing. One funeral director told me in an interview of one reason he went back to school and studied grief,

I wanted to make sure that this stuff about – because you hear people, well, I interviewed with Jessica Mitford, she basically was giving me the bird, so to speak in my face,

saying what you do isn't necessary. Put everybody in a cardboard box, cremate them and they can do their own whatever they need to get through it.

The jurisdictional claims made by funeral directors surrounding grief is both contested and stifled. Funeral societies aim to challenge funeral directors claims at assuaging grief while funeral corporations stifle funeral directors' professional claim in the process of employing them. Both present a challenge to funeral directors' jurisdictional claims, management of stigma, and ultimately not to be defined as "creepy."

CHAPTER 8

FUNERAL DIRECTORS UNDER ATTACK

Consumer Movements and Corporate Control

As shown in the previous chapter, funeral directors claim two jurisdictions. First, in controlling and embalming the corpse the funeral director has a full jurisdictional claim, which is “based on the power of the professions abstract knowledge to define and solve a certain set of problems” (Abbott 1988:70). What is done with the corpse is the basis of funeral directors’ full jurisdictional claim (Cahill 1999; Howarth 1996), but because of the stigma surrounding handling the corpse, funeral directors needed another jurisdictional claim in order to gain credibility, which is grief. As shown in the previous chapter, the funeral director’s expertise in assuaging grief is accomplished through embalming, grief counseling and the funeral performance, but this is a divided claim in which other actors (in this case clergy and psychotherapists), share in the division of labor (Abbott 1988: 73). This divided claim, as well as the claim that grief needs expert attention, leaves funeral directors’ claims vulnerable to a challenge. The major challenge does not come from clergy and therapists, who are funeral directors’ main competition within the broad field of grief counseling, but from consumer movements and corporate control. Organizations such as the modern day funeral and memorial societies do not see funeral directors as providing comfort to the bereaved but as unscrupulous business people taking advantage of vulnerable buyers, and over the last century they have launched a campaign to discredit the funeral industry. In addition, the jurisdictional claim can be threatened by powerful actors who control funeral directors’ work, specifically corporate conglomerates such as Service Corporation International (SCI), Stewart Enterprises and Carriage Industries. These corporations that employ funeral directors

have the power to decide whether and how funeral directors assuage the grief of the bereaved. From consumers and corporations, funeral directors' jurisdictional claim of expertise surrounding grief is being challenged. Consumers, represented by the funeral and memorial societies, challenge the funeral directors' expertise in assuaging grief as well as the necessity of experts in grief. Corporations, in their pursuit of providing customer service for a profit, diminish the autonomy of the funeral directors they employ by limiting their work with grief.

This battle over jurisdictional claims addresses who should be in charge of grief. From a professional perspective, funeral directors claim that they are experts in grief and, working with the bereaved, they offer a professional service that help assuage the grief of individuals. Those who take an anti-professional perspective, such as the funeral societies, claim that grief is best dealt with on an individual level and that family and friends are sufficient in coping with grief. From a corporate perspective, the bereaved are customers who buy goods and services from the corporation, and funeral directors are employed to provide quality customer service. Among the potential consequences of this battle is the reduction of funeral directors' jurisdiction to the tending to the corpse (Cahill 1999; Thompson 1991), thus a further stigmatization of funeral directors.

Funeral and Memorial Societies: Discrediting the Funeral Industry

The story of consumer resistance to the funeral industry starts in the 19th century with burial societies organized by European immigrants to the United States (Sommer, Hess and Nelson 1985). In the early 20th century the Farm Grange organization in the Northwestern United States banded together for mutual benefit, and among those benefits was burying each other (Mitford 1998). Two books, Reverend Quincy L. Dowd's 1921

book *Funeral Management and Costs: A World-Survey of Burial and Cremation* and John Gebhart's 1928 report for Metropolitan Life titled *Funeral Costs: What They Average; Are They Too High? Can They Be Reduced?* promoted simple, inexpensive funerals and argued that the poor were irrational buyers and spent too much money on funerals. While hesitant to indict the entire funeral industry, the authors were critical of funeral directors who took financial advantage of those in grief and called upon the funeral industry or government to regulate the disposal of the dead. Most of all, the authors criticized embalming as a practice interfering with simple and dignified funerals (Laderman 2003). From the Farm Grange organizations the idea of a memorial cooperative spread, and in 1937 Reverend Fred Shorter and his Seattle congregation of the Congregational Church of the People started questioning the embalming and burying practices of the funeral industry (Prothero 2001) and they organized the People's Memorial Association (Sommer, Hess and Nelson 1985). The idea spread, and in 1962 more than two dozen memorial societies (out of about 85 in the U.S.) met in Chicago and established the Continental Association of Funeral and Memorial Societies (Mitford 1963). A memorial society (later to become known as a funeral society), is a non-profit consumer watchdog organization that monitors the funeral industry and lobbies for reforms (Funeral Consumers Alliance 2009). Local organizations also serve their members by advising its membership and the public on their funerary options (an "advisory society"), and/or work with at least one local funeral home to provide low-cost service packages for its members, either informally (a "cooperating society") or formally (a "contract society") (Sommer, Hess and Nelson 1985).

The publication of Jessica Mitford's *The American Way of Death* (1963) galvanized the funeral society movement. In her New York Times bestseller, Mitford lambasted the funeral industry and funeral directors, objecting to lavish funerals based on an "American Tradition" (17). Mitford also challenged the claim that American funerals are based on consumers' desires, arguing that "choice doesn't enter the picture for the average individual, faced, generally for the first time, with the necessity of buying a product of which he is least in a position to quibble" (18). Additionally, she attacked the "half-baked psychiatric theories" (18) that validated the memory picture and grief therapy, and the euphemisms employed in the funeral industry. Importantly, she reframed funeral directors as "merchants of a rather grubby order, preying on grief, remorse and guilt of survivors" (228-229) rather than a dignified profession with specialized skills contributing to the public good. Subsequently, the number of memorial societies increased, and by 1983 an estimated 200 were operating in the United States (Sommer, Hess and Nelson 1985).

Responding to a general increase in public awareness, the Federal Trade Commission began investigating the funeral industry because, according to a 1975 FTC memo,

The Commission declared that it has reason to believe that bereaved buyers are in an especially vulnerable position and that their vulnerability has been exploited by undertakers through a variety of misrepresentations, improper sales techniques, nondisclosures of vital information and interferences with the market. Such practices have, the Commission believes, inflicted substantial economic and emotional injuries on large numbers of consumers (cited in Laderman 2003:134).

In 1978 the Bureau of Consumer Protection issued its report to the Federal Trade Commission, titled “Funeral Industry Practices: Final Report to the Federal Trade Commission and Proposed Trade Regulation Rule.” While not indicting the funeral industry as a whole, the Bureau of Consumer Protection cited abuses within the funeral industry, such as embalming without permission and removal of remains without authorization, and asserted the necessity of stricter regulations because of the vulnerability and ignorance of grief-stricken consumers and the need to make a quick decision (Bureau of Consumer Protection 1978). Subsequently, the federal government imposed the “Funeral Trade Rule” (or “Funeral Rule”) that became fully effective in April 1984. This rule (Laderman 2003:138),

1. Prohibited the misrepresentation of prices.
2. Prohibited loading fees onto the price of caskets.
3. Prohibited forcing consumers to take package deals.
4. Ordered disclosure of various state regulations, especially pertaining to embalming.
5. Created the General Price List, in which funeral directors were required to provide an itemized list of goods and services.
6. Affirmed consumer choices, even if they didn’t conform to traditional funeral services.

These new regulations, while focused on prices, served to delegitimize funeral directors more generally. One claim of professionals is that they are not self-interested; rather, they work to improve society rather than focus on accumulating wealth. The claim that funeral directors are self-interested, and even greedy, serves to challenge the funeral

director's professional claims. Today, the Funeral Consumer Alliance claims over 100 affiliates from 43 states ("Affiliates Directory"2009). The national organization provides informational resources for local affiliates and consumers regarding current laws and consumer rights so bereaved family members are informed when they make funeral arrangements. They serve individual consumers by providing information regarding their legal rights and common unscrupulous practices. They also serve as a watchdog organization of the funeral industry, reporting abuses and lobbying for legislation that promotes consumer rights. Finally, they support local affiliates in disseminating information and coordinate communication between affiliates (Funeral Consumer Alliance 2009). While the aims of the funeral society movement are at odds with the funeral industry, contract societies, somewhat ironically, work with local funeral homes to provide lower prices to consumers.

The Funeral Corporations: Controlling Funeral Directors' Work

Funeral societies played a role in promoting legislation that protected consumers in their choices of funeral arrangements from the possible manipulation by funeral directors. While the government imposed some limitations on funeral directors, corporations imposed others. Service Corporation International (SCI), Stewart Enterprises and Carriage Services have acquired many previously independent funeral homes in recent years. According to the National Funeral Director Association's website, approximately 11% of the 21,080 funeral home in the United States are corporate owned (National Funeral Directors Association 2009). This is a challenge to funeral directors' professional authority and autonomy, in which the funeral directors' authority gives way to that of the corporate conglomerates.

SCI was founded by Robert L. Waltrip, a licensed funeral director since 1952 (Laderman 2003) who started with a family funeral home. By 1971, when it took over Kinney Services, SCI owned 136 units (Smith 1995). In the ensuing years, SCI continued to acquire small funeral homes in target markets, and by 1995 it had owned over 1500 funeral homes and almost 250 cemeteries (Laderman 2003). Its strategy of acquisition is to target urban areas with an elderly population and create “clusters” of funeral homes concentrated in one market, so that much of the operations of several funeral homes can be centralized. In a 1993 article in the *New York Times* by Allen R. Myerson (Cited in Smith 1996:354-355) Waltrip’s son, W. Blair Waltrip, discussed the process of acquiring a funeral home. In the companies “demographic room,” executives and analysts confer over computerized data of neighborhoods that include, in addition to other demographic variables, actual and predicted death rates. Then SCI goes into the neighborhood and tries to buy the “premier home”:

Often, the owners of the home initiate the talks. But even when they don’t S.C.I.’s starting approach is always friendly, especially since the same clans have often owned these homes since their founding. “We try to be very, very diplomatic,” said W. Blair Waltrip, the chairman’s son and executive vice president. He has a finance degree, not a funeral director’s license, and the ways of a Wall Street merger baron.

The younger Waltrip’s first visit to a funeral home owner can seem like a mission of compassion—the the complications of passing the business on to children, the cost of complying with regulations and all the other work, work, work. If by the end of a second visit, the funeral director shows no desire to have S.C.I. lighten the burdens, then Mr. Waltrip might mention that he has also called on the home’s leading competitor.

Still no luck? “On the third contact we tell them we have property zoned and we are seriously considering building a

funeral home,” Blair Waltrip said. That might be on a cemetery that S.C.I. owns, giving the new home a claim on everyone who has a plot....

After the acquisition, the makeover ensues, with new carpeting, furniture, and lighting, bought in bulk to save money. Often, the former owner (most often a funeral director) is asked to stay and work for the company as managers. Through the 1990s and into the 2000s, SCI continued to acquire funeral homes and other ancillary businesses. In 1996, SCI bought Alderwoods, the funeral company that emerged from the bankruptcy of the second largest funeral conglomerate the Loewen Group, for \$1.2 Billion, and in July 1998 attempted to buy Stewart Enterprises. Today, SCI owns about 1,300 funeral homes and 350 cemeteries (White 2008).

Two other funeral corporations are worth mentioning. Stewart Enterprises is now the second largest funeral conglomerate, with 221 funeral homes and 139 cemeteries (White 2008). Stewart Enterprises started as a cemetery business in 1910, but in the 1970s started placing funeral homes on their cemetery grounds. For the purposes of this study, one of the most interesting aspects of Stewart Enterprises in California is its 1997 acquisition of the direct cremation companies the Telophase Society and The Neptune Society (Prothero 2005). These companies started as less expensive alternatives to embalming and burying in direct competition with funeral directors, (Prothero 2001), but are now engulfed within a corporation. Carriage Services, a much smaller company, owned 135 funeral homes in 2007 (Owen 2007). Carriage Services is employing a different strategy of acquisition than SCI and Stewart, and what Loewen did, by focusing more on the quality of the funeral home and its business practices rather than the quantity of homes in a thick market to form a cluster (Laderman 2003).

Corporations, as much as consumer movements, are challenging how funeral directors tend to the grief of those they serve.³⁷ The funeral societies, emerging out of a consumer movement and an anti-professional ethos, challenge the necessity of embalming, the validity of grief counseling and the complexity and costs of the modern funeral. Corporations, reflecting a customer service orientation toward grief, embalm bodies almost as if on a production line, often at a centralized location by someone with no connection to the deceased or the family. Grief counseling is not done by individual funeral directors or even “counselors” at the local funeral home but by calling an expert grief counselor at a central phone number. The funeral is still an accomplishment with the purpose of assuaging grief, but the staff at corporate funeral homes are more constrained in their ability to assuage the grief of bereaved friends and family members than those who work at the independent, sometimes called “Mom and Pop,” funeral homes. Specifically, corporate funeral homes have standardized the grief experience, packaging funerals, centralizing embalming, and contracting with professional grief therapists rather than relying on the expertise of the funeral director. The professional orientation toward grief that funeral directors embrace is being challenged by a consumer rights perspective and a customer service orientation. Without a jurisdiction over grief as the core of their professional domain, funeral directors are left with the most stigmatizing aspects that define their work.

³⁷ A similar process is happening to doctors, in which the rise of consumer knowledge (Haug 1988) and the corporatization of medicine (McKinlay and Stoekle 2001) are affecting physicians’ control over their work. While my focus is somewhat different, this literature led me to apply these ideas to funeral directors and began this train of thought.

Funeral Societies: Challenging Claims

Funeral societies are watchdogs of the funeral industry, but they do more than ensure that funeral homes follow The Funeral Rule. In addition, funeral societies attempt to challenge the claims of the funeral industry. Many of them are working toward making funeral directors obsolete by allowing individuals to plan and implement their own or their loved ones' funerals. Until Americans are willing and able to do so, many funeral societies contract with local funeral homes to provide the least expensive funerals possible. Most of all, funeral societies reject the claims made by the funeral industry, including the ideas that embalming is needed for viewing the illusive "memory picture" and that funeral directors are experts in grief and can counsel the bereaved concerning grief. While they accept that funerals are necessary, they claim that the modern funeral industry is more concerned with profit rather than providing a service, and they promote a low-cost "simple, dignified and affordable" funeral rather than one that is lavish, opulent and expensive.

The first challenged claim is the therapeutic value of embalming. Jessica Mitford's (1963) original *The American Way of Death* challenged the necessity of embalming, whether it is for public health reasons or as a means to view a memory picture. In the chapter titled "The Rationale," she engages in a debate with funeral directors and clergy, challenging them to prove to her, through psychiatric or medical research, that viewing an embalmed corpse has value. Because the evidence provided is anecdotal and based on experience rather than systematic research, she concludes by calling the justifications for embalming "demonstrably flimsy and ridiculous" (95). In her updated edition (1998) she quotes a man associated with the University of

Minnesota's Mortuary Science program who said, while denouncing her books in a 1996 edition of *Funeral Monitor*, "If embalming is taken out of the funeral, then viewing the body will be lost. If viewing is lost, then the body itself will not be central to the funeral. If the body is taken out of the funeral, then what does the funeral director have to sell?" In the next sentence Mitford, as an exclamation to her point that embalming is more economically motivated rather than therapy, says "I could not have put it better myself" (Mitford 1998:64).

The Funeral Consumer Alliance also challenges claims pertaining to the value of embalming. For example, their publication "What You Should Know about Embalming" (2005) states that the only times embalming is required is when the body is being shipped from Alabama, Alaska or New Jersey, or in Idaho, Kansas and Minnesota when the body is shipped by common carrier. Furthermore, in an attempt to challenge the funeral industry's claim that viewing the corpse is therapeutic, they cite a 1990 study by the Wirthlin Group that found that "32% of consumers reported that viewing was a negative experience." In sum, the stand against embalming is that it does not protect the public health and is not necessarily beneficial emotionally to the bereaved, and it is not required by law. The motive for embalming, they conclude, is profit-driven. According to "What You Should Know about Embalming," embalming "gives funeral homes a sales opportunity to increase consumer spending (by as much as \$3,000 or more)."

In many ways embalming is the cornerstone of the funeral industry. Without embalming and restorative arts, much of the curriculum at Mortuary Science schools would be eliminated. This is quite alright with a staff member at a funeral society, who said

I don't think there should be any such thing as embalming and restorative arts.... If you were to show, as I have, a video of an embalming to the American public, embalming would go out.... I think there is a need, in many cases, to see a body.... But I don't think you need to have a body embalmed to see it, and I think colleges—it's not rocket science! You don't need a college for this!

Not only is embalming challenged, but so is funeral directors' expertise in grief counseling. Mitford's first edition showed the connection between embalming and grief counseling:

Lately the meaning of "grief therapy" has been expanded to cover not only the Beautiful Memory Picture, but any number of aspects of the funeral. Within the trade, it has become a catchall phrase, its meaning conveniently elastic enough to provide justification for all of their dealing and procedures. Phrases like "therapy of mourning," "grief syndrome," trip readily from their tongues. The most "therapeutic" funeral, it seems, is the one that conforms to their pattern, that is to say, the one arranged under circumstances guaranteeing a maximum profit (91).

While the funeral societies challenge the value of embalming and expert grief counseling, they do not dismiss the value of funerals. One funeral society staff member told me in an interview that

As a ritual to come to terms with the end of a life, I don't know if it's humanly possible to ignore.... You can't ignore that they are not there anymore. So you must go through some kind of way to deal with it. Everybody's an individual. Now, if you're talking about going through a ritual that has to be defined in a certain way, that I don't feel is important.... The ritual itself should have allowance for as much individuality as possible and not have anything to do with expense, but that is the American way of death.

Because they see the funeral industry as profit-motivated rather than consumer oriented, the funeral societies work to educate the public on having affordable funerals. One funeral society staff member, in Board of Directors' meetings and in my personal

conversations with him, described “the functions of ignorance³⁸,” in which “suppliers and producers make the most of the ignorance of the consumers so that they can have all sorts of [advantages]. And so in a society... any consumer organization... is an advantage to people who have to make their economic way in society.” This ignorance on the part of the consumer concerning the funeral transaction is one of the four special circumstances that Mitford (1998) discusses in *The American Way of Death Revisited* (in addition to ignorance of the law, a mindset that might be affected by grief and pressure to decide on products immediately). The funeral transaction, according to Mitford and others who work in the funeral societies, is a mystery to many and they have set out to educate the public on how funeral directors take advantage of their ignorance and grief. For example, Mitford documented an approach to selling caskets called “the Keystone Approach,” developed by W.M. Krieger in his book *Successful Funeral Management*. This approach divides the casket room into four quartiles, with two above and two below the median price. The objective is to get the buyer to select a casket in the third quartile. If the buyer thinks the casket is too expensive for them they are shown something in the second quartile which is considerably lower in price but not so low as to insult the buyer. The hope is the buyer will not want to go as low as suggested and will be rebounded to the third quartile (Mitford 1998: 21-23).

Funeral societies are consumer watchdog organizations, but in the process they are attempting to provide other alternatives in funeral service. Community Funeral Society emphasized “Simple, Dignified, Affordable,” and the staff member reported that many

³⁸ While my respondent did not say so explicitly, “the functions of ignorance” comes from Moore and Tumin (1949); specifically in terms of the relationship between the specialist and the consumer, in which “Ignorance on the part of the consumer of specialized services... helps to preserve the privileged position of a specialized dispenser of these services” (788-789).

activists subscribe to this notion. Community Funeral Society contracts with local funeral homes to provide low-cost services to the funeral society “subscribers.” In March 2003, Community Funeral Society offered a \$40 subscription, and when the time came to plan a funeral the subscriber could call upon the contracted funeral homes to engage in three of the following four plans³⁹: Direct cremation, in which the body is removed from the place of death, placing it in a combustible container, transported to a crematory and to be cremated and returned to the mortuary (\$635-\$797); Immediate body burial, in which the body is removed, placed in a “simple casket” and transported to the gravesite ((\$670-\$1095—cemetery costs not included); or a “simple funeral,” which includes a body burial plus a “modest funeral service” (\$1100-\$1400—cemetery costs not included). In these simple funerals the costs are greatly reduced, since there is no embalming, expensive casket, or other expensive services. The message from Community Funeral Society is that a simple, low-cost funeral is a legitimate choice.

Perhaps the ultimate choice is bypassing the funeral industry. In Seattle, WA the People’s Memorial Association owns its own funeral home, the People’s Memorial Funeral Cooperative, that “Provides simple, dignified, affordable final arrangements...Our staff will not pressure you or your loved ones to purchase any more of the basic merchandise and services needed for your choice of arrangements” (“People’s Memorial Funeral Cooperative”). Another choice that eliminates the funeral industry is a do-it-yourself funeral. Lisa Carlson (1998), former executive director of the Funeral and Memorial Societies of America, wrote the do-it-yourself guide *Caring for Your Own Dead: Your Final Act of Love*, which is perhaps the most comprehensive guide

³⁹ The fourth plan was to donate one’s body to a medical school.

on the disposition of the dead with as little assistance from a funeral director as possible. Covering laws in all fifty states, this guide instructs survivors in obtaining a proper death certificate, laws surrounding fetal death, transporting the deceased, burial and cremation. This book demystifies the process for the bereaved, focusing not only on the financial savings but on “the act of love.” In her story of disposing of her husband’s body, Carlson writes, “I understood just how easy it would be to let a funeral director take over as I drained my body with tears. But I felt a strong need to express my love and caring for John, even in death” (19). Whether it is contracting with sympathetic funeral homes or doing it oneself, the funeral societies focus on dealing with grief in whatever way is best for the individual, rejecting the expertise of the funeral directors in assuaging grief.

Corporations: Grief and Customer Service

If funeral societies are trying to expand the different ways in which survivors can grieve, corporate funeral homes such as Service Corporation International aim to standardize the grief experience. Corporations often claim that the service is personalized and they are more than happy to provide simple services such as direct cremation or direct burial, but that is not the focus. Rather, standard practices that can be packaged and sold are in the interests of the funeral corporations, often referred to as “conglomerates.” The focus on elaborate and complex funeral services is done in the name of consumer desires. William Henry Kellar and Elisabeth O’Kane (1999) counter Mitford’s criticisms of the funeral industry in the SCI sponsored book *Service Corporation International: The Creation of the Modern Death Care Industry*, arguing that individuals want to spend money on funerals and that a modern day paradox occurred in which “The more people shrank away from death, the more elaborate and expensive the funeral customs became”

(8). According to Kellar and O’Kane, funerals are expensive not because funeral directors are unscrupulous merchants out to take advantage of an unsuspecting public but because the public wants to spend money on an elaborate funeral for a loved one. As the death care industry grows, so does the standardization of funerary practices, and this standardization affects funeral directors’ abilities to apply their own expertise in assuaging grief.

For example, many in the funeral industry support embalming because it allows for a “memory picture” and is thought to be therapeutic. Within corporate funeral homes, it seems that embalming is routine, especially if there is to be a viewing. For example, City Mortuary’s General Price List from July, 2004 states that embalming costs \$500.00, with the following explanation:

Except in certain special cases, embalming is not required by law. Embalming may be necessary, however, if you select certain funeral arrangements, such as a funeral with viewing. If you do not want embalming, you usually have the right to choose an arrangement that does not require you to pay for it, such as direct cremation or immediate burial.⁴⁰

There seems to be some exceptions to this rule regarding embalming and viewing. An embalmer I interviewed at this mortuary told me that embalming is not required by law, but

We encourage you to embalm because if you are going to have an open casket, it’s just a much nicer presentation than a body that hasn’t been embalmed and has been around awhile. And we don’t clean them, if they are embalmed we don’t bathe them and to dress them is not a pleasant task.... But we do have families that want an open casket funeral but do not want embalming, so we’ll do that.

⁴⁰ According to Carlson (1998) this disclosure is legally required by The Funeral Rule.

Perhaps the most controversial aspect regarding embalming at SCI homes is the centralization of embalming. The mortuary I studied had enough cases so embalming was done onsite, but in other clusters embalming is done in a central location. The practice of owning several funeral homes in a cluster and having centralized services at one home goes back to an idea Robert L. Waltrip had in the early 1960s, before SCI was officially formed. Waltrip had owned three funeral homes in the Houston area, and one funeral home was the “hub” of the group, from which most of the business operations came and supported the other two (Kellar and O’Kane 1999). Centralization, over the years, spread to embalming, and in many SCI clusters that have, according to the SCI embalmer I interviewed, a “central care” facility where embalming for several homes occur in one location.⁴¹ Not only does embalming become routinized, but the embalmed body is more of a standardized factory product rather than a craft product treated with specialized attention by the funeral director or a staff he or she closely supervises. One former independent funeral director who sold his business to SCI criticized the practice of centralized embalming,

If it were me, and I called a certain funeral home and I had known in my mind that I think my father was taken to that funeral home, and I find out he’s three towns away in another funeral home, I would not be comfortable with that and it would probably upset me.... I would seem to me that it was somewhat deceptive.

In the corporate funeral homes, the control of whether and where to embalm is more in control of the corporate funeral home than funeral directors that work there. Grief counseling has also been packaged and sold in the corporate setting. At City Mortuary, the people who worked with the bereaved showed compassion and caring in their

⁴¹ Stewart Enterprises also practices centralized embalming (Stewart Enterprises Inc 1998).

interactions, such as soft pats on the shoulder. However, there was not much interaction after the funeral. The general manager and funeral director told me in an interview,

There are a few people who are beyond what I can do, and I refer them, recommend them to a professional who can deal with that, because I don't, in our business, we really don't have enough time to spend with the family after the funeral.... We are not therapists or counselors on an ongoing basis.

The therapy and counseling is bought through a package. According to City Mortuary's General Price List, the cost of the 24-hour Compassion Helpline is \$95.00. SCI offers packaged grief counseling. For a year following the funeral, immediate family members have 24-hour access to a grief counselor with an advanced degree in social work (Dignity Memorial Network Inc. 2003). In addition, there is also the "Picking Up the Pieces" program SCI offers free to families brochures, video tapes and booklets that offers advice on coping with grief. These brochures are written by experts in grief and loss, including: Alan D. Wolfelt, Ph.D., director of the Center for Loss and Life Transition; Eva Shaw, Ph.D., author of *What to Do When a Loved One Dies: A Practical and Compassionate Guide to Dealing with Death on Life's Terms*; and Charles A. Corr, Ph.D., former chairperson of the International Work Group on Death, Dying, and Bereavement. This reliance on experts, with their advice packaged in the forms of brochures, videos and booklets as well as accessed through telephone counseling sidesteps the controversies surrounding funeral directors as grief counselors. SCI's funeral directors are clearly not grief counselors, but professional grief counseling is available to those who need it. In its providing professional grief counselors for the bereaved, SCI is awarding the jurisdictional claim of grief counseling to experts other than their own funeral directors.

As stated in the last chapter, the funeral performance is an accomplished activity meant to assuage the grief of the bereaved. At City Mortuary funerals are accomplished as a matter of routine. More than an accomplishment, they are packaged. In the General Price List, the description of “Traditional Package ‘A’” includes the services of the funeral director and staff, preparation and embalming, dressing and casketing, chapel use, transportation, memorial book and acknowledgement cards, motorcycle escorts, procession signs and maps, pallbearers’ accoutrements and valet parking. The price on this package is \$3730.00, plus the price of the casket. Furthermore, “Deletions of services or merchandise included in a package will not result in a credit to the package price,” so if City Mortuary agrees to a viewing without embalming they would still charge for the embalming. Traditional funerals “B” and “C” are only slightly adjusted. These packages are provided to simplify the process of choosing a funeral. Packages, according to an SCI financial results statement, “are designed to simplify the customer decision-making process...” Furthermore, the packages are more lucrative, with burial packages earning about \$2800 more than non-packages and cremation packages earning about \$1,700 more than non-packages (“Service Corporation International Reports...” 2004).

The standardization of grieving practices is evident in SCI’s centralized embalming, grief counseling program and funeral packages. This is in direct contrast to both the individualistic practices promoted by the funeral societies and the professional expertise espoused by independent funeral directors. Funeral directors at corporate funeral homes do not have control over the embalming process, they resign their expertise in grief counseling to corporate hired grief counselors, and they promote not their own funeral

services but those of the corporation. Through different processes, corporations as well as funeral societies diminish the expertise of funeral directors.

Funeral Workers' Response

Funeral directors, embalmers and arrangers respond, or do not respond, to these attacks in various ways. Many people in funeral work I interviewed had not heard of funeral societies, and those who did were the ones who contracted with their local funeral society or are involved in professional funeral organizations (or both). Those who had heard of them had mixed reactions. One funeral worker whose funeral home contracted with the local funeral society said, "Because there's a lot more choices out there, it is not as necessary as it once was.... In terms of nonprofits in general, I have no problem with it." Another funeral director addressed what he saw as the shortcomings of the funeral societies:

Their hearts are in the right place, of wanting to take care of families so that they are not taken advantage of. My experience with them, which has not been a lot, has been when the Department of Consumer Affairs of California had open meetings.... They'd come and they'd argue, "We see funeral directors doing this and you're not doing anything about it" As you would hear people stand up and talk, it would be people that really don't know the laws, and they would come with things that were ludicrous, and they really didn't know what they were talking about.

Another funeral director, who contracts with the local funeral society to in order to change their views from within, said,

My general opinion is that they are fairly ill-informed. They have taken their viewpoint of funeral service and they believe that it is absolutely golden and really never involved anyone in the funeral industry, so to speak, to share with them a different side of the question.... We

actually have an agreement with our local funeral and memorial society, which is a nonprofit organization, and had a very enjoyable relationship with those folks for many, many years, but from a philosophical standpoint I think they are just a little closed-minded. They've not really given funeral service a fair shake. They looked at it mostly from an economic standpoint, and not from the standpoint of what it is that we have to do to make this living.

While many of the funeral workers I interviewed had not heard of funeral societies, most had heard of Jessica Mitford and many had read *The American Way of Death*. For example, I had the following exchange with an apprentice embalmer:

FW2: You hear a lot of rumors about funeral directors taking the gold out of people's teeth or stealing the jewelry before they go down in the ground or cremating people with people or then there is... there was the lady who wrote that book about the funeral industry

JF: Jessica Mitford?

FW2: Yeah, I guess so. There was her. I think she caused a lot of stir. You know the high cost of funerals.... But I think wow, it's not that pricey. I think about cars, musical instruments, musical instruments are expensive. Sure, okay a casket costs as much as a refrigerator. Maybe caskets are a little expensive, okay.

In addition to the funeral director at Family Funeral Home who referred to Jessica Mitford as "giving me the bird" referenced in the last chapter, another funeral director discussed the impact Jessica Mitford had on the funeral industry:

One of the hardest things is that the media, in the last ten years has demonized the funeral industry, and I would say, without a doubt, wrongly so.... [Jessica Mitford] cast kind of a jaundiced eye on funeral service in America. This is not to say that there are not good and bad people in every industry. However I would say that the lions' share of people in funeral service are doing, number one, a very difficult thing, and she pretty much has turned the focus, and the media has turned the focus on everything the funeral service has people basically being robbed by the mortician, and the truth of the matter is the reason funeral

service costs what it does is because funeral homes have to operate in the same economy that everybody else has to operate in.

Criticisms of Jessica Mitford are quite common in funeral work, but criticisms of funeral corporations are less common. Many in funeral work were hesitant to criticize funeral corporations such as SCI, such as an embalmer who responded when I asked for his opinion on funeral corporations, responded, “They are very large.... They are so big it takes three people to talk about them.” A funeral director criticized the funeral corporations but also stopped short, as shown in this exchange:

FD6: The families lose out when you deal with a company, when decisions are made by people who don't have any hands-on knowledge, and are only interested in making a profit. And I think you lose something when you get away from the family-owned or private funeral homes. Independently-owned funeral homes give you much more personal attention, warmth, and you don't have to go... “by the book”.... You meet the needs of the family rather than the needs of the corporation. I think that the big corporate-owned funeral homes are not in the best interest of the family.

JF: Can you provide a concrete example that would illuminate that point?

FD6: I think I'd rather not.

Another funeral director could provide an example of how corporate funeral homes are less capable of meeting the needs of the family,

I think that the failing in a lot of the large corporations... what happened to some extent is they created an environment where sort of the McDonalds or fast food of funeral service. Everybody who comes through the door gets Meal A, Meal B, or Meal C. There is not a lot of flexibility. In other words, SCI, if they have a family who comes in that wants to rearrange the chapel and set out art work, they're not going to do that. It's just not going to happen.

A few were blatant in their criticisms, such as one funeral worker who said of funeral corporations, “none of them have a good reputation as far as the individual funeral homes go... they’re not considered a good thing at all.” The apprentice embalmer previously quoted in this section discussed how corporate funeral homes buy out independent funeral homes and form clusters,

I feel bad when that family market down the street closed down, so you couldn’t go to it anymore. You know some competition is good, but not if it is going to wipe out everybody.... I think that making it corporate makes it have less personal feeling maybe. It makes it feel more like, well, Jessica Mitford’s book.

Not surprisingly, the most support of funeral corporations came from those who worked in them. A former employee of SCI who worked in their sales department told me, in discussing independent funeral homes, “I don’t think they’re much different than the corporations.” The funeral director at City Mortuary told me why a corporate funeral home is better for families and the staff,

Well they have a lot more resources. They put more money into the mortuary as far as keeping decorated and updated. The older private ones are less likely to do. They have many more packages and options they can give a family which the independents can’t. If someone passes away here and goes to another one of our company mortuaries there is only a \$795 charge for the inter-company. A private funeral home cannot offer, the public that low of a fee and as many amenities as a big corporation.... There are a few down sides to it, but the majority is more positive for the employees and the cliental.

Finally, another funeral director who works for a corporation other than SCI told me,

I have some very good friends who work for SCI... Most funeral homes say “boo, boo SCI,” but that doesn’t mean that there aren’t some very good professional funeral directors that work for them, and probably for the most part... They are a very professional organization that probably watch the regulations more than any other company because they are more suspect... I have no reason not to like them at all.

The most uniform criticism I heard regarding corporations concerns Stewart Enterprise’s ownership of The Neptune Society. The funeral director at Family Funeral Home explained his objection:

They are not a society. They are for-profit company. The American consumer thinks it is a non-profit so they think it is a great idea. Half the college professors that die here... go to the Neptune Society because they think it is a very altruistic thing to do, go to a non-profit to care for me after I die, and in theory that sounds good, but to realize that it goes to a for profit company under the guise of a society... So my opinion on that is that it is misleading to the public. Obviously it invokes a heightened awareness on my part, because I think it is deceptive. Are they a good provider? I never criticize competition. I say they are a fine organization and if in the conversation it can come up and I can let them know it is not a “society” a non-profit I do in a gentle way.

In terms of responding to attacks on their profession, funeral directors have a much easier task in responding to a blatant attack from Jessica Mitford. Although funeral societies’ values are aligned with Jessica Mitford’s and they promoted one another, funeral societies often need to have good relationships with local funeral directors in order to establish contracts for their members. The attacks from corporations are elusive; corporations need funeral directors to survive but take aim against funeral directors’ jurisdictional claims. Corporate funeral homes are still funeral homes with funeral directors, so independent funeral directors might hesitate to criticize corporations because

it may be interpreted as an attack that Jessica Mitford might make. Because of their economic power and ability to control information, funeral corporations are probably a bigger threat to funeral directors than, as one funeral society member said in a meeting, “pipsqueak nonprofits.”

The Different Orientations toward Grief

The fight over jurisdictional boundaries is a fight over how grief should be managed in American society. The funeral directors shown in the previous chapter see themselves as experts in grief, with a professional orientation toward grief. However, the funeral societies see grief as something that is a fact of life, and humans have the capacity to engage in rituals of their choosing and find support without the help of experts. The funeral societies promote an anti-professional orientation toward grief, promoting the idea that grief is to be assuaged on the individual level. One does not need a memory picture, expert advice, or a lavish, expensive funeral to tend to their grief, and the idea that people need experts in grief to assist them is rather odd. For example, in Mitford’s original book she quotes Stanford sociologist Edmund Volkart (95):

My general feeling is that the phenomena of grief and mourning have appeared in human life long before there were “experts” of any kind (psychiatric, clerical etc.) and somehow most, if not all, of the bereaved managed to survive. The interesting problem to me is why it should be that so many modern Americans seem more incapable of managing loss and/or grief than other peoples, and why we have such reliance upon specialists. My own hunch is that morbid problems of grief arise only when the relevant lay persons (family members, friends, children, etc.) somehow fail to perform their normal therapeutic roles for the bereaved—or may it be that the bereaved often break down because they simply do not know how to behave under the circumstances?

The problem, then, is not that humans cannot deal with grief, but in their grief are vulnerable to manipulation by those whose economic interests are contrary to the bereaved. Funeral directors are “merchants of a rather grubby order” out to take advantage of you and your grief, so don’t be fooled. In fact, if you want, you can arrange a funeral for a loved without the help, or with minimal help, of a funeral director. Also, funerals do not have to be expensive to be meaningful, and a simple, dignified and affordable funeral is a legitimate way to say goodbye to a loved one.

The corporations have a customer service orientation toward grief. Grief is something that is to be addressed through putting on a funeral, and customers don’t need to do much of anything except pay for it. A lavish, expensive funeral is justified by a notion of tradition and a claim of what the customer wants and the “traditional funeral” is an expensive one. Funeral packages can be sold to simplify the decision-making process and all funeral directors need to do is put on the show. Embalming is done at a centralized location away from the funeral director’s view, and funeral directors do not have the time or the expertise to engage in grief counseling, but grief counseling, practiced by counselors with advanced degrees, can be purchased as part of a package.

The anti-professional and customer service orientations toward grief are in contrast to the professional orientations. The professional orientations, allowing for some variation, are similar to what I found at Family Funeral Home. There, the funeral directors affirm individual choices while providing professional services. They believe in embalming and viewing as positive practices that serve the bereaved. Embalming is done on the premises and under the control of the funeral director who owns the funeral home. They also engage in informal grief counseling by educating their clients about grief. They

are interested in educating the public about grief, how funerals and funeral directors can help people in grief, and the many choices people have when it comes to dealing with death and bereavement. As for the funeral, they are more likely to emphasize individual choice in how the funeral is performed and tailor the funeral to the needs of the family.

The attack on funeral directors is a battle over how Americans experience grief. Because of the institutionalization of death and dying, death, including grief, became less familiar in American society. At a time when many experts in many fields emerged in modern times, funeral directors emerged to help people through grief. The funeral societies are not only waging a battle against funeral directors and their alleged greed but are advocating a wider cultural change in which grief should be assuaged on an individual basis. The corporate control of the funeral industry aims to standardize funeral practices, resulting in a standardized grief experience. This approach is most offensive to the funeral societies, which is one reason why the funeral society I studied would not contract with corporate owned funeral homes. For some people, as standardized grief experience is what they want, in which they don't need to spend a lot of time thinking about the funeral, embalming, or grief counseling. For others who want a more individualized experience, they can have "simple, dignified, affordable" funerals for their loved ones. But they must take some time and shop around, know what their wishes are, and be prepared to advocate for themselves, often at a time when they are least emotionally capable to do so.

While the consumer organizations and corporations challenge funeral directors' expertise, they still need them. Other than the People's Memorial Association, funeral societies are in no position to directly challenge the funeral industry, and Americans are

not ready to plan their own funerals. Instead, funeral societies rely on funeral directors competing against one another to keep prices down, and they encourage this competition by contracting with funeral homes on behalf of their subscribers. On the other hand, corporations need funeral directors to serve as managers, mostly because of state regulations. The work within funeral homes in general and corporate funeral homes in particular are becoming more itemized; rather than a funeral director being the “chief cook and bottle washer,” their tasks are being performed by counselors and embalmers. However, funeral directors are not needed on their own terms. Neither the funeral societies or the corporations want funeral directors to be able to claim a jurisdiction surrounding grief, and if their claims are successfully challenged or the work is taken away, what is left is the professional jurisdiction of handling the corpse, and funeral directors once again become “creepy” people.

CHAPTER 9

CONCLUSION

The Meanings of Death and Dying

What is the meaning of death and dying in the United States? Contrary to master narratives shown in academic research and popular culture, there are many. These meanings of death and dying vary across institutions and within them. For one to understand death and dying in the United States, one must leave open the possibility of many different understandings, existing simultaneously and often with tension and conflict. Medical institutions, hospices and the funeral industry do not cohere to a single understanding of death, neither across the institutional settings nor within them.

In medical institutions the master narrative concerning the meaning of death goes like this: the medicalization of death and dying resulted in death as the enemy of medicine, and doctors are to fight death with all the technological tools they can muster. Doctors must also maintain an emotional distance from patients in order to keep their equanimity, and religion and spirituality are marginalized because of the possibility of accommodating death. I found this at the County Hospital Intensive Care Unit. Doctors fought death with a vast array of technological tools. They had rules around emotional expression and sometimes became desensitized to their patients' plight. They also tended to not include clergy and chaplains on their teams and some had unreceptive views toward religious family members. But I also found a narrative at County Hospital and University Hospital that views death as a fate better than needless suffering. Both the ICU and palliative care teams loathed the idea of applying medical technology in a futile

attempt to save patients' lives, constituting it as "torture." Furthermore, sympathizing with a patient and their family and even crying over their plight was not only accepted but considered appropriate. In palliative care, chaplains are not marginalized by are integrated into the palliative care teams because of their role in helping to alleviate spiritual suffering. These two orientations toward death—death-as-enemy and suffering-as-enemy—coexist within medicine.

In hospice, the master narrative toward death and dying goes like this: hospice is a social movement that successfully challenged the medicalization of death and dying. Hospices tend to the "total pain" of patients and families, including physical pain and discomfort, spiritual crises and emotional stress. At Hospice on the Farm and Marina Hospice I found this to be true. Both hospices are adept at pain control, both addressed the spiritual crises patients experience and worked to help patients find meaning in their lives, and both tended to the emotional stress experienced by patients and families, especially in terms of bereavement. But another narrative comes into play concerning hospice as a bureaucratic organization that is subject to regulations imposed by the Medicare Hospice Benefit. In order for hospice to survive, it had to become a part of a bureaucratized health care system. Therefore, in constructing its orientation toward death and dying, each hospice must wrestle with the ideals of the social movement and the bureaucratic demands of Medicare. So are hospice workers a part of a social movement that changed how the dying are treated, or are they a part of the health care system that sometimes works against the interests of patients? They are both. To what degree hospice workers embrace each set of ideas not only shapes their work, but shapes how they view their patients.

Within funeral work, the master narrative toward death and dying goes like this: funeral directors are professionals, experts at assuaging the grief of the bereaved. They do this through embalming the corpse to provide a “memory picture,” informal grief counseling, and the funeral performance. This institution’s master narrative might be a little more consistent than medicine and hospice, but there are still some challenges to the master narrative. At Family Funeral Home, and to some extent at City Mortuary and as reported to me by other independent funeral directors, this is the case. The embalmers at Family Funeral Home and City Mortuary took great care to present the corpse as if they are sleeping peacefully to provide a comforting memory picture, and both put on the funeral performance for the family. Informal grief counseling was much more common at Family Funeral Home than City Mortuary; in fact, no one reported to me that they engaged in grief counseling at City Mortuary. Corporate conglomerates challenge this master narrative by reducing funeral directors’ work to providing customer service in the form of embalming and the funeral performance. Centralized embalming turns the corpse from a craft to a product, and the funeral performance is often packaged and not as easily adaptable to individual needs. Funeral societies also challenge the master narrative by challenging the validity and altruism of funeral directors’ work. The anti-professional position of funeral societies is one that says we do not need funeral directors. Embalming is not only not necessary but might be harmful to the bereaved and friends and family can provide comfort to the bereaved better than funeral directors. Instead of being experts in grief, funeral directors are greedy business people out to take advantage of vulnerable buyers.

The fact that there are different meanings of death and dying within these institutions is clear. Why there are different meanings and where those meanings come from is less clear, but one source of these different meanings arise from the interplay between professional expertise, on the one hand, and internal debate, external resistance from below, or inhibiting of that expertise from more powerful sources. In medicine, the conflict around the proper orientation toward death and dying is one within medicine. Whether death or suffering is the enemy not only varies by circumstances, but can vary between and within hospitals, medical specialties, and even units. The death-as-enemy and suffering-as-enemy orientations toward death and dying are internal debates among colleagues. This is different than hospice, which started as a social movement challenging medicine's treatment of dying people. As a result of the social movement, hospice became synonymous with end-of-life care and hospice workers are adept at addressing physical pain and discomfort, spiritual crises and emotional distress. Inhibiting hospice's ability to care for the dying is the Medicare Hospice Benefit, which mandates to all hospices how they must be structured and for whom they can provide care. Funeral directors and their expertise in assuaging grief are challenged by both corporate conglomerates, who have the power to limit the professional skills of the funeral directors they employ, and the funeral society social movement that challenges the necessity and the altruism of funeral directors.

Institutions that serve the dying and bereaved are unique in that we come across them from time to time, especially when we are in crisis. In these times we receive the crash course when we are least able to learn it, but perhaps another impediment to learning about death and dying is that the crash course itself is not logically organized

around one narrative. Nevertheless, instead of death being a part of everyday life as it once was, dying and death is institutionalized to the extent in which, in most people's daily lives, we do not interact within these institutions. Therefore, we get part of a story framed as one master narrative, such as medicine fighting death, hospice as a social movement, or professional funeral directors assuaging grief. Rarely are we told about the orientations toward death and dying that require our loved one to be taken off a respirator, demand that the patient no longer needs morphine, or questions the necessity of a trocar.

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