

## **Abstract**

MONAHAN, MOLLY BERNICE. *Rationality Unveiled: Philosophy and Practices in a Hospice Organization*. (Under the direction of Barbara J. Risman.)

The modern hospice movement began in the 1960s as a response to the rationalization of care for the dying. Ironically, however, hospice organizations have themselves become increasingly rationalized over time, with the advent of Medicare certification and conventional accreditation practices. Despite this, contemporary hospice practitioners must still attempt to follow the holistic philosophy which originally made hospice unique. Thus, they encounter a dilemma of trying to enact an alternative philosophy while being tied to the conventional. This dissertation is a case study of a hospice organization in the Southeastern United States (“Hometown Hospice”). I use observational and interview data to illustrate the rationalization process and discuss its consequences for hospice practitioners. I show how the attempt to follow an alternative medical philosophy while also pleasing regulatory bodies created mixed messages for front-line workers at this organization. Next, I discuss how the workers used humor to manage the unpleasant emotions that resulted from this dilemma. I then discuss how Hometown Hospice perpetuated racial and class inequalities common throughout health care, despite their interdisciplinary team approach to fulfilling the philosophy of holistic care. I conclude with a discussion of other sites where the dilemma between philosophy and expected practices occurs.

**RATIONALITY UNVEILED:  
PHILOSOPHY AND PRACTICES IN A HOSPICE  
ORGANIZATION**

By

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## **Biography**

Molly B. Monahan was born on July 22, 1973 in Erie, Pennsylvania. She lived there (in the same house!) until she graduated from Villa Maria Academy in June of 1991. She went to the Pennsylvania State University that fall. She stayed “undeclared” until deciding on English as a major late in her Sophomore year. The next semester, she took her first Sociology course. She soon changed her major. She graduated in December of 1995 with a B.A. in Sociology and a minor in English. She began graduate work in Sociology at North Carolina State University in the fall of 1996. She defended her master’s thesis, a content analysis of newsmagazine articles concerning violence against women, in May of 1999. She then passed preliminary exams in the areas of Sociology of Families and Sociology of Inequalities. Soon after, she was married to Brandon Loughridge, another graduate student – and fellow cohort member – at N. C. State. In the fall of 2000, she began the work that has culminated in this dissertation. She is currently living with her husband in Shaker Heights, Ohio, and teaching at Baldwin-Wallace College.

## Acknowledgments

This project has taken years to accomplish. And I firmly believe, true to my sociological perspective, that there is no such thing as an individual accomplishment. In fact, in order to give credit where credit is due, I would need to start very early in my life, and track and thank all who have helped me get to this point. I wish I could. I am sure that I would leave people out, because of the inadequacies of memory. I am also sure that my “Acknowledgments” would then be longer than the dissertation itself! So I will limit myself here.

Of course, I need to thank my committee. Barbara, Barbara, Barbara (Risman): writing your name once just is not enough. You have fulfilled everything on the list of “what a chair should do.” You have pushed me intellectually, prodded me to keep working, advocated on my behalf, and complimented me where appropriate. And your turnaround times were amazing! I honestly don’t know how you did everything you had to do, and still got feedback to me so quickly. I appreciate that more than you know. I have enjoyed getting to know you over the years, and our conversations about so many things. Thanks for being such a good feminist mentor for me; your influence will be long-lasting.

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words of kindness, or votes of confidence. That has been invaluable for me – indeed I think it is important for any graduate student to have someone on their journey who has fulfilled what you have for me. Thanks.

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My husband Brandon Loughridge and I have been a team since the beginning of graduate school. I will never forget the first meeting of our cohort. I liked him immediately. Then, I saw the “dancing bears” patch on his backpack, and I thought to myself – I cannot date a Deadhead! Well, that was just one of many myths that he has helped me dispel over the years. We have been fortunate in that our skills, interests, and preferences have complemented each other so nicely. Whether in sociology, housework, pet care, or entertainment preferences, we overlap just enough to feel compatible but not so much that we are cookie cutters of each other. I appreciate him most for what a good listener he is. And for his capacity to express his care for others. Thanks, Brandon, for working so hard to understand me, for your excellent skills of negotiation, and for being so

easy to be around. I appreciate it. (Ariel Lang, you did a good job! Thanks for your support as well).

My parents, Robert and Connie Monahan, also deserve recognition. Throughout my life, they have supported me while letting me choose what I wanted to do. I am not sure any of us knew how long this journey would take, or where it would lead me. Despite that, they have supported me each step of the way. They have listened to me go on and on about all aspects of this process. They have asked questions and kept up with all the deadlines and all the contingencies. They have congratulated me at points, and pushed me at others. Perhaps best of all, they have provided enjoyable times for me to forget about all of it. Thanks, mom and dad.

My parents are not the only family members to have been great supports. Aunt Claire (Kennedy), I have come to believe, was placed on this earth to be my familial intellectual lighthouse. She is always there – for questions, advice, or commiseration – and she represents the successful completion of the doctoral process. After all, if I didn't finish, how would I explain that to Aunt Claire? Thanks for being my academic and feminist support, for as long as I can remember.

My siblings Megan, Michael, and Valerie Monahan have also been understanding throughout this process. They have shown me, through questions like, “When is that big test you have to take?” or “How is your Conclusion chapter coming?” that they are paying attention, and that they care how things are going for me. It is important that I have not felt pressure from them, only

concern. As well as a genuine wish that I finish, and that I feel satisfied with the work I have done. My siblings are also enjoyable to be around, and our visits have been much needed breaks from school and work. Thanks, too, to Kara, Maggie, and Patrick Monahan, our nieces and nephew. You show me the joy of discovery from a child's perspective. You allow me, indeed encourage me, to just be goofy sometimes, to relax, and have a good time. I need that.

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Finally, I would be remiss if I did not thank everyone at the organization that I call Hometown Hospice. You welcomed me into your work space, and allowed me to observe you and ask you questions for many months. Thank you for your willingness, indeed at times eagerness, to help me understand the work that you do.

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## Table of Contents

Chapter 1	
INTRODUCTION.....	1
Access, Data Collection, and Analysis.....	6
Access.....	6
Data Collection.....	7
Data Analysis.....	12
Preview of the Study.....	16
Chapter 2	
THE RATIONALIZATION OF CONTEMPORARY HOSPICE: HISTORICAL DEVELOPMENTS IN THE MODERN HOSPICE MOVEMENT.....	20
Precursors of the Hospice Movement.....	20
The Hospice Philosophy.....	23
Early Hospice Organizations and Increased Standardization.....	25
Hometown Hospice in Its Two Eras.....	30
Hometown Team Meetings as Rationalized.....	37
Routinization.....	38
Efficiency.....	43
Documentation.....	46
Medicare Regulations: Recertification.....	50
Medicare Regulations: No Aggressive Treatment.....	62
An Addendum: The Irrationality of Rationality.....	73
Rationalization and the Provision of Care.....	75
Conclusion.....	82
Chapter 3	
MIXED MESSAGES FOR PROFESSIONAL FRONT-LINE WORKERS: HOMETOWN HOSPICE'S ATTEMPTS AT MERGING TWO DISPARATE HEALTH CARE MODELS.....	84
The Contrasting Components of Two Models of Patient Treatment.....	85
Components of the Dominant Medical Model.....	85
Components of the Psychosocial Model.....	87
The Mixing of the Models and Its Consequences for Workers.....	90
Specialization of Skill, Practice, and Tools.....	90
Patient Control.....	96
Prioritization of Physical Problems and Physical Solutions.....	103
Objectivity Versus Subjectivity.....	110
Maintenance of Professional Distance from Patients.....	116
Existing Research on Health Care Models.....	122
Conclusion.....	125

Chapter 4

COMPLAINING THROUGH JOKING: HOMETOWN WORKERS’ CHALLENGES, AND MANAGING UNPLEASANT EMOTIONS THAT RESULTED..... 128

    Challenges, Unpleasant Emotions, and the Necessity of Humor..... 129

        Bureaucratic Requirements..... 130

            Documentation..... 131

            Medicare Regulations..... 135

        Family as the Unit of Care..... 140

        Working With Primary Physicians..... 146

        Residential Facility Staff..... 148

        An Exception..... 156

        Accounts for, and Legitimation of, Humor..... 157

    Conclusion..... 159

Chapter 5

INCLUSIVE RHETORIC AND THE MAINTENANCE OF EXCLUSIVITY: HOMETOWN’S TEAM APPROACH TO CAREGIVING AND THE INEQUALITY IT DISGUISES..... 161

    The Rhetorical Usefulness of the Team Approach..... 161

        The Team Approach as Different and Superior..... 162

        Team Membership as Inclusive..... 163

    Contradictions in Their Use of the “Team Approach”..... 165

        Exclusion of Aides from “Team Meetings”..... 165

        Other Contradictions..... 166

        An Ironic Account for the Contradiction..... 168

    Managing the Contradiction Between Rhetoric and Reality: Home Health Aide Appreciation Week..... 169

        Analysis of the Appreciation Week..... 172

    How Hometowners Benefited by Having an Inclusive Team Approach..... 175

        How Nurses in Particular Benefited from the “Team Approach”..... 177

    How Professional Hometowners Benefited from the Aides’ Exclusion..... 181

        Maintenance of Homogeneity..... 182

        Exclusion of Aides’ Interpretations..... 184

    Why the Aides May Not Have Pushed for Inclusion..... 187

        Their Definition of Work..... 187

        Pay Differentials..... 188

        Comparison Referents..... 189

    Conclusion..... 192

Chapter 6	
CONCLUSIONS.....	194
Rejecting Scientific Rationality While Working Within Conventional Medicine.....	197
Hospice-Appropriateness.....	197
Documentation Requirements.....	199
Team Meetings.....	201
“Team Approach”.....	202
Residential Facilities.....	204
Other Health Care Sites.....	205
Where Do Similar Challenges Occur?.....	208
“Alternative” Teaching.....	208
Conventional Constraints.....	212
Organic Farming.....	217
Conventional Constraints.....	220
A Summary Statement.....	223
WORKS CITED.....	225

## **Chapter 1**

### **Introduction**

I remember watching my uncle die, at St. Vincent's Hospital, in May 1995. I was not actually there at the time of death. But my sister and I brought him to the hospital in the first place. We were there when the nurse asked him to gauge his pain on a scale of one to ten (he said "eight"). We were there when he was diagnosed with end-stage liver cancer. And we, with other family members and friends, visited him frequently over several days as he declined.

I always felt awkward that there were so many of us there, crowded around his bed and outside his room. There was another man in the room with him, and any visitors he received had to squeeze by our crowd as they walked into and out of the room. The thin, transparent curtain was always drawn between them, but I never felt that either my uncle nor the other man had sufficient privacy. The day my uncle died, there was a particularly large crowd of us. We cried and hugged and squeezed each others' hands. Several of us approached Uncle Dick and said Goodbye to him in our own ways.

And the whole time, the other man lay in the bed on the other side of the curtain, coherent and alert. Even in my grief I thought about him, and what he might be feeling in that situation. I remember thinking that it seemed inappropriate for my loved one to die in an unfamiliar milieu, with a stranger lying in the other bed so near him. I lamented our family's loss of privacy, with other patients, unfamiliar hospital workers, and visitors all around us. And I

wondered, as I still do, whether my uncle would have chosen that to be the setting for his death, if he had had the choice.

My uncle was not the first family member to die in my lifetime. But his death coincided with an enlightening course I took in college called “Death and Dying,” which focused on American processes of dying as well as rituals associated with death. It was during that course that I was introduced to the concept of “hospice.” It was a brief introduction, but I learned the basics of hospice care, particularly its focus on familiarity of surroundings, and pain control. I became intrigued with the hospice philosophy of caring for the dying, and I remain so to this day.

In January of 1996, I was introduced to a family whose members were soon to become a profound influence on my life. I needed a job for seven months (between college and graduate school), and they needed a child caregiver. The four young children’s mother, Kathy, had a fast-growing type of breast cancer. She needed treatment as well as hospitalization, and her illness and exhaustion precluded her from being the children’s primary caregiver.

I met this family and developed an instant affinity for them. Caring for these children quickly became more than just a temporary job. It became a meaningful contribution to a family who was going through a profound process of illness and change. For seven months, I cared for the children six days a week from morning till night. Indeed, I became a surrogate member of the family.

For periods, Kathy was in the hospital. Other times, she was recovering at home. She persevered through many months of rigorous treatment. She told me

that because of her age and the swiftness of the cancer growth (as well as her willingness), the doctors “threw everything at [her] but the kitchen sink. And then they threw that in.” With each check-up, her doctors were pleased to tell her that she was improving. The treatments were successful in staving off the spread of her dreadful disease.

By August, when I left for graduate school, her treatments had become spaced out enough that we were all optimistic for the future. Kathy herself always remained hopeful. She credited her faith, in God and medicine, for her optimism concerning her prognosis. Indeed, her optimism, combined with her doctors’ continuous awe at her resiliency, created a sense that the cancer cells really were just fleeting occupants of her body. I, for one, never thought of her as “dying.” I thought of her as “sick.”

I remember being disappointed in others who had never met the family, when they acted as if her impending death was a foregone conclusion. It was difficult to explain to people that Kathy’s family’s house did not feel like a house in which someone had a terminal illness. When Kathy was home, she was not bedridden. She was coherent. Yes, she was tired, and no, her appetite was not very good. But she was sick, and she was getting better. At least that was what we all thought and hoped.

And we had every reason to think and hope that, until the next summer. She was feeling better than she had in weeks when she went in for a routine check-up. She had been cancer-free for months. And I, having taken on Kathy’s optimistic attitude myself, began acting as if she was back to her pre-cancer self.

We talked on that June day for almost an hour when I was getting ready to end the conversation. It was then that her voice changed a bit and she said that she had to tell me something. I realized that she had been trying to squeeze this information in before, but I was keeping the conversation at such an upbeat level that it had not seemed appropriate. She told me that the cancer had returned. And she was still hopeful, and she still talked of treatment. But the statistics and the science of it began to overpower my abstract faith and optimism. I got off the phone and cried.

The next time I saw her, Kathy told me some good news. Not about her illness, but about an upcoming trip that was being planned. She was going to venture to the former Yugoslavia to a holy place to which she had been devoted for many years. Though we all knew that her body was exhausted, she became energized in her telling of the trip. I realized later the momentousness of it – that this was a trip she wanted to make before she died. And she had to take it at 39 years old in order to achieve that.

By the time Kathy returned from her voyage, she had markedly declined. She had lost much of her mobility and she was easily tired. Treatment no longer seemed like a viable option. I received a call just before Thanksgiving of 1997 that she had taken a sharp turn for the worst, and that she was hospitalized. I flew home from North Carolina to see her. For the second time in two years I was going to St. Vincent's Hospital to see a terminally ill loved one. My initial visit with her was a good one – telling stories, reflecting, laughing together with Kathy and her family. But by the end of my long weekend, Kathy was on morphine

almost continuously, for pain. She drifted in and out of lucidity. Despite all the attempts to stave it off, death was near. Kathy's husband wished for her to die in familiar surroundings. He decided to call hospice in.

Before Kathy was transported home from the hospital in an ambulance, a social worker from hospice came and met the family. I was in the room when she introduced herself to everyone. Though I was grieving, I was intrigued by this woman. I had known about hospice as a philosophy, but this was the first time I had met someone who actually worked for hospice. It struck me that she entered people's lives at such a poignant and emotional time. I wondered about her and her work. This was the beginning of my curiosity about the people who work for hospice, and the work that they do.

Kathy did not have hospice care for very long. She died less than two weeks after she was brought home. She died in her own bedroom, with her husband nearby and her children downstairs. She was not in pain, but she was probably not as coherent as she would have liked. She was 39 years old.

I did not realize it then, but Kathy's experience was in many respects typical of hospice patients. She had advanced cancer when she was admitted. She had endured several rounds of treatment, and had reluctantly decided to forgo any more. She was given morphine for pain. Her family had not opted for hospice care until very close to her death. She died at home, and had hospice care for a very short period of time.

My intrigue with hospice work stayed with me, but I did not seriously consider it as a research topic until I completed my graduate coursework and



prelim exams. As I reflected on the research I had done to that point, I realized a theme of caring work running through it. Many of the papers I had written had been about the work involved in caring for others. In that time I had also had some practice with, and developed an affinity for, qualitative methodology. By the end of my process of narrowing down a research topic, I had become excited at the prospect of weaving together my different interests by doing a qualitative analysis of hospice work.

### **Access, Data Collection, and Analysis**

#### *Access*

I was fortunate enough to gain research access to the first hospice organization I contacted. I called the southeastern organization (that I call Hometown Hospice) initially in late November of 2000. I asked the receptionist if I could talk with someone about the possibility of doing research there. After a few moments of thought, she transferred me to the volunteer coordinator. She was in a meeting, so I left a voicemail for her. A few days later I received a call from the social work manager (also known as the clinical counseling manager) of the organization. She left a message for me, saying that she was returning the call I had made to the volunteer coordinator.

Ten days after her initial call, I met with the social work manager in her office. We talked for over an hour about my potential research project. I told her that I was proposing a semi-inductive, qualitative research analysis of hospice work, and that I was mostly interested in those working directly with the patients

and their families. I asked her about the possibilities of doing observations and/or interviews with those employees.

She suggested that I primarily observe the regular “team meetings” of the workers. She said that patients decide upon admission to the agency whether to give permission for students to sit in on meetings where practitioners discuss their situations. She said that “80 to 85% of the patients say it’s okay” for students to do so. She said that I would have to get permission from the interim executive director and the nurse manager, as well as sign a confidentiality statement, in order to do research there. Indeed, she facilitated that process for me.

#### *Data Collection*

With permission granted, I began observations at Hometown Hospice in February 2001. My initial foray into observations was a staff meeting of social workers and chaplains. The next week, I began observing the more frequently held “team meetings,” as well as some of the daily “admit meetings.” During the nine-month process of observations, I also observed several other kinds of events that were held at the organization. These included but were not limited to: nurses’ aides’ staff meetings, a nurses’ meeting with the executive director, a presentation given by a professional “humorist,” and an appreciation lunch given on behalf of the nurses’ aides.

Virtually all of the interaction I observed occurred within the confines of the agency’s walls. Since the interactions that the workers had with patients and families occurred elsewhere (in hospitals, homes, nursing homes or on the phone),

I did not collect data on interactions between the practitioners and their patients or the patients' families.

I acknowledge that I am limited in what I can say about the processes involved with hospice work without data that come directly from practitioners' interactions with patients and families. However, the strength of this research is that I was privy to the goings-on backstage, where patients and families were not around. My analyses focus on the organization's employees themselves: the expectations of their work; their emotional responses to those expectations; the constraints involved in accomplishing their work; and the unintended consequences of their actions.

It is important to know the social context of the organization in order to fully understand the processes involved within it. There was a hierarchical ordering of the employees, but it was not too complex. At the head of the organization was an executive director. At the time of my access, they were in the process of hiring a new director. The financial officer held the position in the meantime. The new executive director was a white man who had been trained as both a registered nurse and a lawyer, and had prior administrative experience in health care.

Below the executive director in the hierarchy were those who held managerial positions in the organization. These included the social work manager, the nurse manager, the office manager, the home health aide supervisor, and the volunteer coordinator. All of these were white women. The social work manager had authority over the "clinical counseling staff," namely the social

workers and chaplains. The office manager supervised those in the office staff, such as the receptionist. Others in supervisory positions had authority over those in the positions of their respective titles (e.g., the nurse manager supervised the nurses). In this study, I periodically refer to the executive director and the various managers collectively under the umbrella term “management,” to convey them as having positions of authority in the organization. Members of management interacted with patients and families themselves only rarely.

Those who were directly involved with patient care made up the bulk of the organization’s workforce. These were the nurses, nurses’ aides (or “home health aides”), social workers, and chaplains. At any given time during my observations, there were about ten each of nurses, nurses’ aides, and social workers. The great majority of nurses, and all of the social workers, were white women. All but two of the nurses’ aides were black women. Most of the nurses and nurses’ aides worked full-time, while about half of the social workers were full-time. There were three chaplains, all of whom were white. One was a full-timer and two shared a full-time workload. In this study, I refer to these people collectively as “front-line workers,” to convey their direct and (often literally) hands-on interactions with patients and families.

Finally, there were people in the organization who primarily served as consultants for the front-line workers. There were three physicians who were available for consult during team meetings (which I discuss below), one for each team. The physicians were available for calls during other times, but their primary jobs were elsewhere. Except for the rare case, the consulting physicians

did not see the hospice patients themselves. There were a few situations during my observations when one of the physicians happened to be a patient's primary physician. Otherwise, the physicians acted only as consultants, not as hands-on doctors.

There was also a pharmacist in attendance at the meetings, who primarily gave suggestions concerning drug options and dosages. The pharmacist had been with the organization since its inception. Perhaps as a result of this, she also gave advice about other aspects of patient care, such as bureaucratic rules and regulations. The pharmacist, too, rarely saw patients directly. She acted as an outside advisor, and a liaison to the organization's primary pharmacy.

As I suggest above, the data I collected were primarily from observations of meetings and other events that occurred at the organization. (The other data come from interviews with the workers, which I discuss later). The meetings I spent the most time observing were "team meetings" (referred to as "team" by the participants, as in, "Are you going to team today?") and "admit meetings," (called "admit" by the participants).

Hospice organizations which are Medicare certified (like Hometown), use what they call a "team approach" in caring for their patients. The care teams consist of nurses, nurses' aides, social workers, chaplains, and volunteers. At the organization I studied, there were two primary teams, each responsible for a different area of the county geographically. "Red team" covered the northern part of county while "blue team" covered the southern part. There was also a team

focused on caring for hospice patients in particular residential facilities, with which the organization had contracts.

Upon admission, each patient was assigned to a care team. During admit meetings, the practitioners discussed the patients who had been admitted the prior day (or, on Mondays, over the weekend). Those practitioners who would be responsible for the patients' care were told the patient's diagnosis and a brief history about his/her illness progression, as well as any aspects of his/her life experience that were deemed important.

Team meetings were held weekly to discuss patients. The participants included nurses, social workers, and chaplains, as well as one of the three consulting physicians, the consulting pharmacist, the nurse manager and the social work manager. The meetings took place in what they called the "large conference room," which had several long tables placed in the shape of a rectangle, at which we sat, facing each other.

For the first six months of my observations (from February through July 2001), I observed at least one admit meeting a week, all three team meetings (blue team, red team, and residential facility team), as well as other various events. For the last three months of my observations (from August through October 2001), I observed two team meetings a week (red team and blue team). Admit meetings typically lasted less than an hour. Team meetings ranged from 1½ to 2½ hours long. Combining these and other events, I spent over 200 hours observing at the organization.

During the meetings, I sat quietly and took notes. I wrote down what was said, and by whom (using pseudonyms.) I kept track of as much of what was happening as I could, noting facial expressions and nonverbal gestures wherever feasible. I typed up my field notes as soon as possible upon leaving the organization, to fill in other details as I typed.

To buttress the field data, I interviewed various workers in the organization, both formally and informally. I conducted one-on-one interviews with 12 workers: four social workers, three nurses, three nurses' aides, and two chaplains. These interviews ranged from one hour to 2½ hours long. I also rode around with a nurses' aide for a morning, talking with her between patients. And I had many informal conversations with the workers before and after meetings and other events, during which I talked with them about their work.

I tape-recorded the formal interviews, with permission from each of the interviewees. I then transcribed them word-for-word (using pseudonyms for confidentiality purposes). I kept track of the more informal conversations by making "jottings" whenever I could (Emerson et al. 1995). These became part of my field notes for whatever day they occurred. Altogether, my observations and interviews culminated in over 2000 pages of data to analyze.

### *Data Analysis*

Analyzing qualitative data is a continuous process. Even before entering the field, I wrote about my expectations for what I would find, my motivations behind the project, and the emotions that I was experiencing in relation to the project (cf., Kleinman and Copp 1993). Throughout my observations and after, I

reflected on what was occurring in the field. I kept my reflections, and my analysis, separate from the original data that constituted my field notes.

Reflecting on what was occurring (for example, comparing what was happening to what I had thought would occur), often went hand in hand with analyzing the data I was collecting.

Upon entering the field, for example, I was quickly struck by how many patients the organization had in its “census” – close to 100 at any given time – and by how short the patients’ stays were – two weeks on average. I had expected the workers to spend long hours with patients for significant periods of time, and these pieces of information contradicted that. It eventually became clear that the workers saw these as constraints on their work. These early facts triggered me to take note of other constraints, how they were invoked, and their consequences. Eventually, this became an analysis of bureaucratic constraints on the workers, as well as the potential consequences they had for the care given to patients and families (see Chapter 2).

The process of analyzing data entailed reading and re-reading my field notes, coding and re-coding the data, writing analytic memos, and reading various research literatures. I developed a general coding scheme for my field notes after having collected several months of data. I added to, and took away from, these original codes as I continued to collect data. The codes included what Emerson et al. (1993) refer to as “open codes,” where general themes or issues were marked, e.g., emotion mentioned, humor example, team invoked, caregiver complimented.



These were developed into more “focused” codes, where certain specific topics were identified as particularly important.

The codes and memos informed each other throughout the analytic process. I frequently went back to the original data to see if the codes were important or still appropriate, and to see if the data fit the patterns I was identifying in the memos. As Emerson et al. describe the process of analyzing field notes, “From reading comes coding and written memos which direct and redirect attention to issues and possibilities that require further reading of the same or additional field notes” (p. 144). The data themselves are the ultimate test of any hunches a researcher might have.

As others have noted, there is always the potential for a field researcher to want to “go native” (Shupe and Bromley 1980) or “convert” (Lofland and Lofland 1995). I began this project sympathetic to hospice care. And I have often wondered in my adult life whether I should be a social worker rather than (or in addition to) a sociologist. I certainly had moments of consideration during my data collection as to whether I would be more useful and more satisfied as a hospice worker than as a researcher of hospice work. I see this as a benefit to my analysis rather than a hindrance, however. This tendency of mine to consider what it would be like to be “one of them” is consistent with interactionists’ task of seeing participants’ lives from their perspectives, as a path to understanding (Blumer 1969). My periodic wishes to be part the group actually helped me in the process of analysis to remember to look at what was occurring from their perspectives as well as my own.

Though I have confidence in the data I collected, I also acknowledge the power I have as a researcher. I chose which meetings and events to attend, I asked the questions in the interviews, and I ultimately wrote the analysis. In order to conduct an analysis, it is not enough to simply restate the words of the participants. I looked for patterns in the data and interpreted those patterns. In the process of writing up what I found, I chose which data excerpts to use where. I was cognizant of this, and I contextualized the excerpts as much as I could while weaving the patterns together.

Field researchers, as Kleinman and Copp (1993) argue, do not take what is said by their participants at face value. Instead, we see what people say as accounts to be analyzed. The challenge is to balance skepticism with empathy. I was skeptical about the participants' intentions, their accounts of their work, and their interpretations of what was occurring. But at the same time, I attempted to empathize with the workers, to see the real constraints they were working under, and to give them the benefit of the doubt concerning their efforts to do the best work they could do under the circumstances.

I set it as my goal to understand their work as completely as possible given the data I collected. I attempted to see what they were trying to do, what problems they faced, and the sometimes unintended consequences of their actions. I worked at making this a fair, accurate portrayal of hospice work at this organization. It is likely that not everyone involved will be comfortable with this analysis. But that is normal. This type of analysis points out contradictions in, and unintended consequences of, behavior. I had the privilege of spending time

and effort poring over the interactions of these people and to analyze what occurred. The people I studied had to focus on living their everyday lives. My job has been to analyze their work.

### **Preview of the Study**

Hometown Hospice is only one of many such organizations across the country and around the world. In Chapter 2, I contextualize Hometown Hospice within the larger scheme of the hospice movement. I discuss the precursors of the movement, as well as its challenges and changes over time, particularly in the United States.

I show that their philosophy is what makes hospice unique. In fact, modern hospice is often defined as a philosophy rather than a place or a building (Mesler 1995; Mor 1997). Despite variations in organizational mode, region, and services offered, hospices share a philosophy of continuous, patient-centered care for the terminally ill that is palliative (focused on pain and symptom management, not cure), holistic (not just physical but also emotional and spiritual), and provided by members of an interdisciplinary team. Individualized, palliative, holistic, and interdisciplinary: each aspect of this philosophy is a response to what has been called rationalized care for the dying. The hospice philosophy is one of many which questions the sole reliance on rationality in modern society.

Yet, the majority of hospice organizations throughout the country are now certified through the Hospice Medicare Benefit, and/or accredited by the Joint Commission on the Accreditation of Hospitals. The requirements of these regulatory bodies of conventional medicine fit the principles of rationalization. In

Chapter 2, I argue that hospice, like other successful movements, has become rationalized over time. This development was ironic, however, as the movement was begun in response to the bureaucratization of care for the dying. I then document evidence of rationality at Hometown Hospice. I show how the rationalized elements of their work constrained and irritated them, and I discuss some ways in which these elements had consequences for the care they were able to provide.

Hospice organizations were originally designed to be an alternative to the dominant biomedical model of health care provision. But over time, in order to survive as an organization, Hometown Hospice was in part captured by the very biomedical model it was set up to resist. Though the workers themselves did not discuss it in these terms, I argue in Chapter 3 that what resulted were conflicting sets of guidelines for front-line workers to follow in their everyday work: one which followed the biomedical model, and one which followed the more psychosocial orientation that originally made hospice care different. I discuss these models, and show how the conflicting expectations embedded in them both created challenges for workers who were trying to do a good job, and benefited management by allowing them to keep the organization running successfully.

Despite the fact that working with the dying is typically seen as serious and saddening work, Hometown workers frequently used humor when they talked with each other. In Chapter 4, I show how the workers used humor in order to accomplish certain interactional goals. The use of humor allowed them to complain about the challenges involved in trying to follow the regulations that

the dominant medical model requires, while simultaneously attempting to enact a holistic philosophy. This meant working within a bureaucratic organization which requires commitment from people as varied as patients' families and primary physicians, and staff at residential facilities. They used humor in order to complain about these causes of unpleasant emotions (such as frustration, aggravation, and powerlessness) while still sounding like sympathetic professionals. Indeed, humor appeared to be a necessity as a Hometown employee. They recognized that humor may be seen as inappropriate outside of the organization, and made strides to justify the use of humor within their social context.

In Chapter 5, I take a critical look at the interdisciplinary team approach used by hospice workers to fulfill the philosophy of holistic care. I argue that Hometowners used the rhetoric of teams to sound inclusive as well as more effective than other providers of care to the terminally ill. However, despite their rhetoric of inclusivity, they maintained exclusive boundaries and in turn perpetuated the race and class inequalities that exist throughout the health care industry. The lower status and predominantly black nurses' aides – who spent more time with the patients than other team members – were not included in the team meetings. I discuss the consequences of this exclusion, including how various Hometown workers benefited from it. I also discuss why the aides themselves did not insist on being included.

Hospice workers are not the only providers of health care who are constrained in their attempt to follow a philosophy that questions the sole reliance

on scientific rationality. Indeed, any “alternative” (to various degrees) health care organization whose members choose – for any number of reasons – to engage with the conventional, are then constrained by that tie to the conventional, in following an alternative philosophy. This is likely to become more common as the demand for alternative medical practices increases among the general public (Schneirov and Geczik 2002).

But the dilemma is not unique even to those in health care. As I discuss in Chapter 6, alternative public school teachers must attempt to follow pedagogical philosophies that question scientific rationality, while being held accountable for the results of standardized tests that assess students’ acquisition of “the basics.” Likewise, organic farm practitioners who oppose the reliance on scientific rationality in modern agriculture must attempt to do so while following certification regulations set by the government. Though their philosophies differ from the conventional, they may be constrained in how alternative they can be, considering their contexts.

I argue that hospice workers and organic farm practitioners who work in certified/accredited environments and alternative public school teachers are “insiders-on-the exterior.” Despite their philosophies, they are not true outsiders, but they do work on the margins of their respective conventional arenas. Though their philosophies make them unique in their fields, they are not as different as their alternative philosophies suggest. In the end, they can say they are different, but still maintain the security and legitimacy that comes with being affiliated with the conventional.

## **Chapter 2**

### **The Rationalization of Contemporary Hospice:**

#### **Historical Developments in the Modern Hospice Movement**

The concept of hospice has been traced to ancient times, and has had various meanings throughout different eras. In this study, I am concerned with the “modern” hospice movement, beginning in the late 1960s and early 1970s. I start this chapter by discussing the precursors of the modern hospice movement. I then show how the movement has changed since its inception. More specifically, I argue that hospice has gone through a process of rationalization over time. This development is ironic in the case of hospice, for reasons that become clear in this chapter. I then indicate many of the aspects of rationality that are evident at the organization I call Hometown Hospice, including routinization, efficiency, documentation, and rules and regulations. I discuss the intended and unintended consequences of this rationality for the people involved, throughout.

#### **Precursors of the Hospice Movement**

The initial leaders of the hospice movement were mainly responding to social changes within medicine and healthcare that occurred during the process of industrialization in the West. During this time period – approximately the mid 19<sup>th</sup> to early 20<sup>th</sup> century – theories of disease (e.g., germ theory) and knowledge of treatment advanced so that the probability of death from infectious diseases decreased markedly (Glazier 1974; Ward 1998). As a result, more people lived

longer before reaching the dying phase, and that phase lengthened as chronic illness became more common than infectious diseases.

In addition, before this period, there was little knowledge of the importance of sanitary conditions in hospitals and other medical settings. Once people understood the preventive capabilities of sanitation, healing care became more possible (Cancian and Oliker 2000). With these and other advances, infant mortality rates decreased and life expectancy rates increased substantially during industrialization. All of this is tied to the increasing prioritization of biological elements in devising diagnoses and cures, over the previously preferred holistic (though admittedly uninformed) model. Thus, the transformation in medical knowledge during the late nineteenth century and throughout the twentieth century brought with it the dominance of the “biomedical model” of healthcare.

Prior to industrialization, people in Western areas such as the United States were more likely to die in their homes. Death was likely to happen quickly, and to be a result of illnesses that can now be relatively easily treated with antibiotics and other medical interventions. It was not uncommon to be around dying people. Caregivers of the sick and dying were more likely to be non-certified, unpaid family members or religious people, than medical professionals such as doctors and nurses (Bullough and Bullough 1969; Lorber 1997; Cancian and Oliker 2000). Indeed, physicians had not yet achieved the legitimate authority status that we now attribute to them. Instead, religious people such as clerics were more highly esteemed in most realms, including medicine. It is not surprising, then, that care for the sick and dying tended to be non-



technological in nature. As medical theory and treatment advanced, physicians also gained legitimacy and prestige through professionalization (Siebold 1992).

By the middle of the twentieth century, sick and dying people were more likely to be cared for in hospitals than in their homes. In 1900, for example, 20% of deaths took place in hospitals, whereas by 1977, that proportion had increased to 70% (National Center for Health Statistics). People were also more likely to receive treatment by medical professionals such as certified physicians and nurses. And that treatment was more likely to be technological in nature. Medical research had resulted in a tremendous increase in the medications available to the general public, as well as an increase in testing and surgical procedures to cure the ill and/or extend their quantity of life.

These changes resulted in increased bureaucratization. As hospital staff increased, their division of labor became more specialized. A healthcare hierarchy developed as physicians worked to increase their occupational prestige both by claiming expert knowledge and by gatekeeping information (Lorber 1997). Nurses who tried to achieve full professional status were blocked by doctors, who wanted the status of “curers” all to themselves. In order to gain as much status as possible, nurses with more training – mainly white women – have segregated themselves from those with less training – mainly women of color. This has created a nursing stratification system in that RNs claim higher status than nurses’ assistants (Cancian and Olikier 2000). As in any bureaucracy, people in each position of the medical hierarchy have had specific jobs to do, and each have had other workers who supervised them or took orders from them.

Bureaucratization involves more than hierarchical relations, however. Government regulations also increased as the provision of medical care became more complex. And paperwork became important, as patient care required documentation in order to be seen as legitimate. As the number of patients seen by medical professionals increased, care became more predictable and more routinized.

These trends continue, but they have not occurred without contestation. Many people have expressed concern about the treatment of the sick, and in particular the dying in Western industrialized nations. Within this group, the common perspective is that such treatment is overly bureaucratized, impersonalized and inappropriate. It has been argued that the sick and dying are often treated as diseases to be cured, rather than people who need care, and that invasive medical techniques are being used past their utility. This argument forms the basis of the modern hospice philosophy.

### **The Hospice Philosophy**

Cicely Saunders, a British physician, has been credited as the catalyst for the hospice movement in America. By the time she came to the U.S. for speaking engagements in the mid-1960s, she had a well-formulated philosophy concerning ideal care for the dying, and there were plenty of people who shared her perspective. She and others criticized conventional healthcare as dehumanizing, particularly for the dying. They rejected mainstream treatment of the dying as rationalized: more concerned with efficiency, problem solving, and routines than with seeing each person as a complex human being in need of individualized care.

In her perspective, dying people need palliative, holistic, and focused care, with the ultimate goal of total comfort. To that end, she began St. Christopher's Hospice in England in 1967, a free-standing inpatient unit for the terminally ill that is generally thought of as the model for modern hospice care in the U.S. (Mor 1987).

Saunders' philosophy quickly gained momentum in both England and America. Researchers have pointed to many reasons for this groundswell of support. Mainly, the hospice philosophy fit well with other movements going on at the time. The most obvious is the death-with-dignity movement that is affiliated with Dr. Elizabeth Kubler-Ross. Her perspective and Saunders's melded well together, and they helped each other gain support for their causes. The hospice movement also incorporated ideas from the holistic health movement, the women's health movement, and the home birth movement, which were going on simultaneously (Abel 1986). Some workers from within conventional medicine wanted to reform what they saw as inadequate care for the dying, while family and friends of people who had died also became personally involved to make changes (Levy 1982). Other factors that helped early hospice leaders gain support were the growing willingness of people to talk about death, and the realization of the rising cost of healthcare, particularly for the chronically ill and dying (Mor 1987). The members of all of the disparate groups within and outside conventional medicine who criticized treatment of the dying, had obtained a leader in the charismatic Saunders.

Modern hospice is often defined as a philosophy rather than a place or a building (Mesler 1995; Mor 1997). Despite variations in organizational mode, region, and services offered, hospices do share an underlying philosophy, which can be described as: continuous, patient-centered care for the terminally ill that is palliative (focused on pain and symptom management, not cure), holistic (not just physical but also emotional and spiritual), affordable, and provided by members of an interdisciplinary team. In the hospice philosophy, the family is the unit of care, in that patients' families are seen as deserving of emotional and spiritual support. Of course it is worth repeating that all of these elements are part of a philosophy; it can be seen as an ideal. How, and how well, the philosophy gets put into practice varies tremendously from hospice to hospice.

### **Early Hospice Organizations and Increased Standardization**

The first modern hospice in America was Hospice Inc., which opened in 1974. And in contrast to St. Christopher's in England, it offered home care services only, when it began. This has been a primary difference between the development of hospice in the United States, and in Europe. European hospices have typically operationalized the "continuous care" aspect of the philosophy through the provision of inpatient services with round-the-clock hospice practitioners. Whereas in the United States, hospices have typically provided home care, with the continuity enacted through the offer of on-call services that people can use on an as-needed basis. This is partly because the St. Christopher's model is so much more costly to run (Levy 1982; Paradis and Cummings 1986).

Hospice Inc. did eventually add an inpatient facility as part of its services, but it remains primarily a home care-based organization.

After Hospice Inc. was opened, the number of organizations called “hospice” grew quickly. Early hospices were primarily volunteer-based, receiving their funding from community donations and agencies such as the United Way. The use of volunteers allowed them to save money. Some were able to temporarily offer services free of charge. Many of the initial leaders eschewed talk of finances, seeing such discussion as necessarily diluting the more romantic goal of compassionate, holistic care for the dying (Abel 1986).

From the beginning, hospice care has been offered in a variety of organizational types. The most common have been: freestanding hospice facilities like independent home care programs, unaffiliated with other organizations; facilities affiliated with home health care agencies, some of which have contracts with hospitals or nursing homes; and hospital-based organizations, typically in the form of hospice units within hospitals. Currently, 42% of American hospices are freestanding, another 42% are affiliated with hospitals (and hospital systems), and 22% are home health agency-based (National Hospice and Palliative Care Organization, 2000).

Early on, there was concern about the use of the word “hospice” for varying types of care and services. In 1977, leaders from several major hospice groups met to form the National Hospice Organization (NHO). They had many goals, but mainly they met to exchange information and devise standards of care for the growing number of hospices around the country (Mor 1987). The NHO

was influential in lobbying for the reimbursement for hospice care from Medicare, and in gaining hospices accreditation: two major (and controversial) historical developments that I discuss in more detail below.

The first financial support for hospice from the federal government came in the form of grants from the National Cancer Institute in 1978. These grants were not only to hire staff and provide care in the three hospices selected, but also to fund research in these hospices concerning the costs associated with that care. In a continuation of financial involvement from the government, the Health Care Financing Administration invited hospices to apply to participate in a study to determine costs of hospice care. Of the over 200 which applied, 26 were chosen, and for a period of time, all of their services were reimbursed by Medicare. Over a dozen other hospices were chosen as controls. By the time the report by the Congressional Budget Office determined that this legislation would provide substantial savings, the otherwise conservative Congress of 1982 was willing to overwhelmingly pass, as part of the Tax Equity and Fiscal Responsibility Act (TEFRA), the Medicare Hospice Benefit. In 1985, an amendment was added to cover hospice care for Medicaid patients as well.

Under the TEFRA legislation, a patient's care is eligible to be reimbursed by Medicare only if the patient is given six months or less to live by a physician. This regulation has numerous consequences for an organization, which I discuss further below. Also, in order for a particular organization to obtain the Medicare reimbursement certification, it must offer both home nursing services and hospice inpatient care. Hospices are reimbursed a fixed, daily rate for each of four

categories of hospice patient services: routine home care; general inpatient care; inpatient care providing a respite for family caregivers; and continuous home care. The rate is paid for each day the patient is under an agency's care, regardless of the agency's actual expenses. There is also a cap on what they will pay per year, per patient. Full reimbursement for inpatient care is limited to no more than 20% of all hospice patient days. An interdisciplinary team of hospice practitioners must keep financial and clinical control of all patient care. Chaplain, volunteer, and bereavement services must also be offered, although at the time of the passage of legislation, these services were not reimbursable. Bereavement services have since been added to the list of care that can be reimbursed.

In addition to the TEFRA legislation, the NHO worked with the Joint Commission on the Accreditation of Hospitals to develop standards for voluntary hospice accreditation. These standards went into effect in January of 1984. They include the requirement that the patient and family must be seen as the unit of care, in that services should be offered to the patient and his/her family. Also, interdisciplinary team members available to the patient/ family must include at least a physician, nurse, social worker, spiritual counselor, volunteer, and provider of bereavement services. The focus must be on symptom management. Inpatient services must be offered in addition to home care, and services must be available 24 hours a day, seven days a week, in whatever setting.

As all of these developments were taking place, more and more hospice practitioners saw grants and community donations as too limited for fund provision. This has drawn many to apply for and receive certification for

Medicare reimbursement, as well as accept coverage from third party payers such as insurance companies. And in order to survive in what has been seen as an increasingly competitive health care environment, many hospice agencies have felt it necessary to be accredited by the Joint Commission. In the process, hospice care has become increasingly standardized.

These changes in hospice funding and legitimation clearly follow a Weberian path. Weber argued that in order for a social movement to survive, certain changes must occur, including routinization (Bendix 1960). As James and Field (1992) argue, a charismatic movement, such as hospice was at the beginning, can maintain that quality only if it remains small. As the movement progresses and its numbers increase, an administration becomes necessary, and this leads to increased bureaucratization and routinization.

In the case of hospice, this is an ironic progression. After all, the movement arose *in opposition to* the bureaucratized care of dying people. The people involved in this movement agreed to the basic underlying premise of the hospice philosophy: compassionate, comfort-driven care for the dying. But they had differing levels of idealism, different ultimate goals, and they disagreed on the best ways to enact the hospice philosophy. Their ultimate goals varied from modifying mainstream medical care from within; to offering separate, unaffiliated alternatives to such care; to wholly revamping conventional care. Remaining separate from the established order proved to be impossible, mainly because it costs too much to go it alone, but also because hospices have needed legitimate support from those outside the movement, for referrals, and for a pool of eligible



workers (Abel, 1986; Paradis and Cummings, 1986). Though the most idealistic of hospice supporters may still dream of wholly altering medical care to fit a hospice philosophy, the furthest the movement has gotten is to offer another option to at least a small proportion of those who are dying at any given time.

Among those within the movement, there has been plenty of controversy concerning Medicare reimbursement and accreditation. To some, they are seen as destroyers of the original hospice philosophy. To others, they are considered compromises to the philosophy that are begrudgingly necessary. While to still others, they have been welcome changes, seen as good for hospice (Abel 1986; Paradis and Cummings 1986; Mor 1987; Mesler and Miller 1996). Those opposed to the changes have had to change their minds, endure cognitive dissonance, or bow out altogether. Medicare certification and accreditation are now simply part of the hospice provision of care, and this occurred over a relatively short period of time. Currently, over 90% of hospice organizations are certified for Medicare reimbursement, and more than 60% are accredited by the Joint Commission (National Hospice and Palliative Care Organization, 2000). Several researchers have concerned themselves with the challenges these developments pose for hospice as a movement (cf., Abel 1986; James and Field 1992; McNamara 1994).

### **Hometown Hospice in Its Two Eras**

The hospice organization studied here, which I call Hometown Hospice, is a microcosm of the many changes that the hospice movement more generally has gone through. Hometown was begun by a small group of medical practitioners in

the early 1980s. It began as a grassroots organization, with more volunteers than paid employees. As a result, the division of labor was not very complex. For its first several years, the organization was run completely on community donations and grants. It was not certified for reimbursement from third party payers, nor was it accredited. The census, or number of patients receiving care, stayed relatively low. Hometown's early practitioners eschewed talk of business and finances, instead preferring conversations about patient care.

Presently, Hometown has mostly paid employees, with volunteers playing a less significant role than in the past. Compared to the early years, its division of labor is more complex, specialized, and hierarchical. The organization still partly depends on community donations and grants, but most of its funding comes from the federal government in the form of Medicare and Medicaid reimbursements. Hometown is now accredited by the Joint Commission. They are reviewed every several years, and by many accounts this is a difficult, time-consuming process. When I asked why they continue to pursue it, one of the managers said that it is a "prestigious label," that it is "like having letters after your name."

Hometown's census averages much higher than before any of these developments, ranging from 85 to 104 during my tenure there. As a result of all of these changes, the provision of care was more regulated, and the paperwork of the organization had increased tremendously. Financial concerns were also more at the forefront than in the past, with fears of audits concerning whether the hard monies were spent and saved appropriately.

In interviews, a few of the more veteran employees gave me accounts of the changes at Hometown in the past 15 years. They discussed the history of the agency as if it existed in two time periods: grassroots/volunteer and Medicare-certified/professional. The following account is from Eileen, a woman who had held several different positions in the agency and was at the time of the interview working on outreach to the community. She gives a picture of “before” and “after” and the fears associated with the change:

To give you a picture of the change. ... I can remember [another veteran employee] in team meetings, sitting there nursing [her baby] during team [meetings] (She giggles). We were grassroots. We were coming out of that. The Hospice Medicare/Medicaid benefit had just been approved the year before. And we were coming into big time. And like I said people were really worried, [she whispers] “they might think we’re a business.” And we would literally say that word like it was dirty, and whisper it, you know. Nobody thinks [she whispers] “we’re a business” now. (Eileen, p. 90)

In her account, this veteran Hometown employee emphasized the importance of appearance to non-hospice others. The shift from what she called “grassroots” with its nonconventionality (e.g., the allowance of breast feeding at an agency meeting) to Medicare certification and increased organizational complexity (or what she calls “coming into big time”) brought with it fears that Hometown may become, or more importantly may be seen as, a “business.” This was one of many examples where a business model was juxtaposed against a compassionate care model. She found the fears to have been misguided, however, because from her perspective, certification by Medicare did not lead them to become a business. Instead of seeing Medicare certification as a negative development, she saw it as positive, as is indicated in the excerpt below.

We talked further about one of the by-products of Medicare certification, which is an increase in the “census,” or number of patients currently on board with hospice. In her perspective, this was a good thing for hospice. In the following passage, she tied in other related changes. She showed that she was aware, for instance, of the preoccupation that some hospice practitioners had with increased bureaucratization and increased technology, yet she saw these changes in a positive light:

Eileen: When I came on board, our average census on any given day was somewhere 35 to 40. And now it’s around 100.

Molly: And so how do you feel? I’m wondering if you have mixed feelings about increasing the census. Do you?

Eileen: No.

Molly: That’s something you want to do.

Eileen, nodding: Just because I want to see more persons have access to what this type of care means to themselves and family. When I first came here, the agency was going through that huge struggle of leaving grassroots and going to professional. And I can remember roundtable discussions and people passionately implying that if we left grassroots, we would leave all that hospice meant, and that people would no longer get good care. And having lived through that decade, I can certainly see that people get just as wonderful care. Albeit perhaps a bit streamlined, albeit a few more forms and high tech. When I first came here, there were no cell phones, there were no pagers. When you got ready to go out and make visits, you left a list at the front desk of who you’re going to see. And if they needed you they just called around till they got ya (She giggles). So here we are now with all the gadgets, and the laptops, and I find that the care and compassion given to patients and families is exactly the same as it was 12 years ago. ... That hasn’t changed a bit. ... So that the clinical care is wonderful. The compassion is there. We’re just having the opportunity to care for more people. (Eileen, p. 21)

Again, she discussed the shift from “grassroots” to “professional.” This was clearly a momentous change in the organization, in her view. She knew that it brought with it a process of rationalization, or in her words “streamlining,” “more forms,” and an increase in “high tech[nology].” But she wanted to make clear that she did not see this as changing the “care” and “compassion” that made hospice what it was. She insinuated that I may see the two as mutually exclusive, and that she had heard this before. A sign of rationalization is a focus on quantities, in a paradoxical attempt to determine quality through numbers (Ritzer 2000). She did exactly this by stating that increased “access” and “opportunit[ies]” for more people to have hospice is an improvement in and of itself.

In an interview with a different veteran employee, who had been there during the process of applying for Medicare certification, she shared her thoughts on the various changes the agency had gone through over the years. Again we see a positive perspective:

Molly: What are your thoughts on the Medicare certification?

Connie: I think it’s a good thing. You know, initially, [giggle] I’ll never forget, our executive director said when they were introducing the whole idea of becoming Medicare certified, and she said “It’s only gonna require one piece of paper that the staff would have to fill out.” And I laughed and I said [giggle] “you’ve gotta be kidding, the federal government and one piece of paper? I don’t believe that for a minute!” ... So that was, having to get used to all of that paperwork, you know....But in the long run of course, it was necessary. And it’s a good thing, both for the agency to survive, but also for families and patients. I mean it’s a good deal, you know.

Molly: You mean because now it’s getting paid for.

Connie: Yeah. It's getting paid for. We never, we never billed anybody. See our source of income up to that point was solely through donations and grants that they called "soft money." So you could never count on, you know, "hard" money coming in. It depended on the generosity of the community. And it became apparent that we were gonna have to go the route of Medicare.

Molly: Okay, so that was a choice.

Connie: That was a choice, oh yeah.  
(Connie, p. 5)

Again, we see that this employee understood that Medicare certification brought with it an increase in the paperwork of the organization. She argued that this was worth it, however, for the agency to survive. She also said that certification was good for families and patients, but then said that the agency never billed anybody anyway. So in essence, she attributed the application for Medicare certification more to the need for the agency to have "hard money" than to the benefits it gave to patients and families. The latter was more of an afterthought, and is a statement that only holds up if increasing the census indeed benefits patients and families (which is, of course, open to debate).

As I said above, Medicare certification and increased bureaucratization go hand in hand. This includes, of course, a more complex and more specialized division of labor. In the following excerpt from later in her interview, Connie gave an indication of the transformation of the division of labor at Hometown, as it shifted from a primarily volunteer organization to one with more paid employees:

Molly: Were there chaplains before Medicare?

Connie: Yes, there were. We had a chaplain on staff. We had a social worker and a chaplain.

Molly: One. One of each.

Connie: Yes, one social worker, one chaplain. We had the executive director and um, a business/office person and a receptionist/secretary and there were about, well I was part-time, the other nurse, so we made the equivalent of one nurse. And we had the D.O.N. [Director of Nursing] and one other nurse so there were three of us. ...And then you had, and then we also had the director of volunteer services.

Molly: Oh right. Okay so there were volunteers.

Connie: Oh yeah, we had a large component. And back in those days, volunteers did a lot of hands on care. They would do a lot of what the [nurses'] aides do. Volunteers actually did hands on care. Now they didn't actually do nursing care in terms of blood pressures and, although we also used volunteer nurses. We had volunteer nurses. So they, the volunteer nurses did do nursing care. Made visits and that sort of thing, monitored medications and we used volunteer nurses for on-call. I mean it was a big volunteer organization.

Molly: But it sounds like now you probably aren't allowed to do that.

Connie: No... you might want to talk to [other veteran employee] because she was, she spearheaded trying to utilize volunteer nurses and sort of supplementing the staff nurses and ultimately I think it came out of her recommendations that it really wasn't working. What I recall about it was that part of it was, you know, when you're dealing with volunteers, it's much more difficult to, the accountability is much more difficult to deal with. In terms of documentation, in terms of frequency of visits, uh, in terms of communication, just that, that whole piece of accountability. ...we finally just sort of chucked it. (Connie, pp. 6-7)

In the fifteen years since Connie started at Hometown, the number of paid employees had increased from less than ten to close to seventy. The number of people in lower level positions (mostly to be found in the form of certified nursing

assistants (CNAs)) had increased, as well as those in supervisory positions. Thus, a more specialized hierarchy had developed over time. Concurrently, volunteers were doing less and less of the care, as their role had changed to a strictly supportive one. In other words, volunteers could help patients and their families with practical duties such as transportation, and they could spend time with and converse with patients and families, but they no longer did “skilled” nursing care. Connie used terms like “accountability” and “documentation” in her reasoning for why volunteers no longer did nursing care. These are terms which indicate a rationalized workplace, one that relies more on professional (i.e., legitimate) and paid (i.e., more accountable) employees than on unpaid workers.

### **Hometown Team Meetings as Rationalized**

I spent the majority of my time at Hometown observing what they call “team meetings,” where practitioners meet to discuss patients. As the census had increased over time, managers found it necessary to divide the county geographically, and give workers particular areas in which to visit patients. They called the northern part of the county Red Team territory, while the southern part was for Blue Team workers. The majority of those doing patient care visited patients in their homes. These teams met as follows: Blue Team met on Tuesday mornings and Red Team met on Thursday mornings. Hometown Hospice also had contracts with many residential facilities in the county, and some workers specialized in those locales. These folks were also divided into Blue and Red, and each team met every other Tuesday afternoon. To show how times had changed, when the veteran employees above first began working at Hometown, all patients



would get discussed at *one* team meeting a week. It was not uncommon to hear them wax nostalgic about those days.

### *Routinization*

The team meetings I observed were indicative of a bureaucratic, rationalized workplace. They were, for example, highly routinized. Each team meeting began at the same time on the same day of every week, in the same room. Right before each meeting, someone paged through overhead speakers that the meeting was about to begin (“Blue Team meeting is starting now in the large conference room”). One of two managers typically issued the page. On the few occasions where both of them were absent, another manager would take their place. And without exception, the proxies neglected to make the page indicating the start of the meeting. Inevitably, many people did not arrive. This was seen as highly irritating and perplexing for those taking the place of the absent managers. In fact, on more than one occasion, I had to remind them to issue a page. Once they did so, people began to arrive.

As folks arrived, they signed in before they sat down. The following excerpt from my field notes illustrates Hometown routine and how intimately tied it was to both documentation and regulation:

The two new nurses – Loretta and Sharon – are in there.

Chaplain to the new nurses: You’ll be joining us for team today?

Manager to the new nurses: You need to sign in.

Loretta (pointing to another nurse at the sign-in area): She’s signing us both in.

Manager: You need to sign yourself in.

Loretta: Okay, even this once?

Manager: Yes, or else the scheduler will wonder who's messing with the sign up sheets.

The two new nurses get up and walk over to the sign-in area.  
(Notes 16, pp. 46-47)

The new workers were not only taught the sign-in routine in this exchange, they were also taught the importance of following rules, at all times. The new nurse implied that this was not a big deal, but she was quickly told otherwise. This was not the last time that she questioned, and/or was annoyed by, an aspect of the routine. (She also quit after less than five months with the agency).

After signing in, people sat down at varying spots at the different tables, which were set up to form a large rectangle, with open space in the middle. People commented when they were sitting in a different place than normal. One time, for example, a chaplain said she was sitting "on the nurses' side." And on one occasion, after I had been observing for six months, a social worker even said she was sitting in *my* spot. My behavior, too, had become routine enough to be noticeable.

For each meeting, there was a list of patients to be discussed, that had been printed from the computer and copied for each person in attendance. The computer was often reified in references to this list. People said that "the computer lists the names," or that "the computer left [a patient's] name off the list." This absolved any human being of making an error. It also left many

workers frustrated with technology, particularly when a certain patient's name kept getting left off a list.

The list itself was important not only for people to follow along in the meeting, but also because prior to the meeting, one of the office workers used that list to pull the pertinent patients' binders from a back room, and place them on a cart. These binders contained the patients' "chart, care plan, and med list," a mantra I heard many times. Directly before the meeting began, the facilitator of the meeting rolled the cart into the large conference room. This was so routine that when the cart did not "appear" in the room, people looked around quizzically and asked where the cart was. This usually meant that the facilitator was not there, and eventually someone else tracked down the cart.

The facilitator routinely got the cart and rolled it next to the spot where the nurse manager (or someone taking her place) would sit. The nurse manager was then responsible for pulling each binder out as that patient was being discussed, and handing it to the physician to peruse as necessary, and putting it back on the cart when that particular patient discussion was finished. One time, the physician's helper had gone to take a telephone call during a patient's discussion (not an uncommon event), and the stack of binders that she had pulled and put on the table next to the physician had been gone through. When the next patient's name was called, the physician looked around for a moment, then reached over to the cart, searched exaggeratedly for the name on the spine of the binder, found the correct binder, and pulled it off the cart with a small huff. She indicated the break in routine with her behavior.

Each patient to be discussed had a separate printed sheet with pertinent information on it, that had to be filled out at each team meeting. They called these “team sheets,” and their purpose was to document the patient’s discussion during the team meeting. There was always a stack of team sheets placed next to the sign-up sheet. After workers signed up, they picked up (some or all of) their patients’ team sheets.

As each patient’s name was called by the facilitator, the person with that patient’s sheet then introduced the patient. She typically said the patient’s age, primary physician, diagnosis, “ecog” level (measurement of ambulation), payer source, and whatever medical supplies the patient and family had in the home. Next, she listed what they called the “problems” for that patient. Some problems were seen as nurse problems and some were seen as psychosocial problems (for the social worker and/or chaplain). Nurse problems included “breath patterns ineffective,” “cardiac output decreased,” “nutrition inadequate,” and “nausea/vomiting.” Social work problems included “grief,” “coping difficulty individual,” “coping difficulty family,” and “legal issues unresolved.”

If they did not say each of these components in their introduction to each patient, someone would likely ask them. One time, for example, a new social worker, who had not been present at many team meetings, introduced a patient. She began by saying: “[This patient] is a 38-year-old patient of doctor [Smith] with cancer of the prostate...” Then she paused. She had given the patient’s age, primary physician, and diagnosis, and she was not sure what to say next. The

facilitator said: “List all the problems, then discuss issues.” The social worker proceeded to do as she was told. She was taught the routine script.

On several occasions, directly after a patient’s name was mentioned but before the introduction was done, someone began to speak about the patient. For example, one time, after the facilitator named the patient (“James Smith”), instead of going through the typical list of information, the patient’s nurse, who did not even have the patient’s team sheet, began by saying: “Dear James. I’m looking at decreasing my visits to once a week.” As people looked at her, she said to the patient’s social worker, who had his team sheet, “I guess I better let you read the problems.” She showed that she spoke out of turn, and she corrected her own mistake.

Other times, the person with the patient’s sheet only gave a partial introduction. Virtually every time that occurred, either directly thereafter or sometime during that patient’s discussion, someone asked “what are his problems?” or “what’s his ecog level?” or “what’s his primary diagnosis?” Rarely did one of the pieces of information get left out for long.

After each introduction, they briefly discussed the patient. Typically, the patient’s nurse began the actual discussion, even if it was a chaplain or social worker who introduced the patient. Each problem listed would typically be addressed in some way. For example, a nurse may say “nausea/vomiting: he is taking Compazine, and that is going well.” At times, the nurses asked for assistance with the patient, typically about medication, or a social worker asked for help, typically for a social services resource suggestion.

The speaker sometimes told a very short tale about a patient or family, but it was typically relevant to the medical or psychosocial discussion at hand. For example, a nurse once was talking about a patient's dementia, and she said, "His speech is less frequent – occasionally one word. Although when he does respond, it's appropriate. [She laughs in the retelling]. I have to tell you. Mrs [Jones – his wife] told him to open his eyes and he said, 'There ain't nothin' much to look at.'" Several people laughed. And she went right to the next problem on the sheet. So the discussions were not exactly robotic, in that they were often lighthearted, but they were routine.

### *Efficiency*

Efficiency was also highly valued in the meetings. An interesting change in the meetings occurred soon after I began observing. At first, the teams discussed each patient (at least) once a month. To give an indication of how many patients might then be discussed at each meeting, during my second week of observations, the facilitator began the meeting saying they had a "huge list," and it was 14 patients. Soon after, someone in the agency realized that they were not following Medicare regulations, which were to discuss patients every two weeks. The managers at the meetings forewarned the others that they were going to start discussing patients every two weeks. At the beginning of one meeting came a typical admonition:

Facilitator/manager: We need to look at patients every two weeks. So think about what you're reporting on. If you want to talk a long time about each patient and be here three hours, that's okay, but if you'd rather not, ...

Pharmacist: I've been to team meetings in other places where they were three hours. It's not fun.

Facilitator/manager: Then let's focus on what has changed, what's different, and what needs to be addressed.

Other manager: Keep it short, sweet, and to the point.

Facilitator/manager: If there's no change, say no change.  
(Notes 3, p. 13)

With the implementation of this regulation, they typically discussed 20 to 25 patients at every meeting. And the meetings usually ended within two hours. This meant less than five minutes spent on each patient, on average. And some discussions were much shorter than that. A nurse or social worker report could be a few sentences and still be considered complete. Here is an example of a short but complete social work statement, read by a manager because the social worker could not attend the meeting: "Cindy [the social worker] provides ongoing support to the family and discusses caregiving issues. They have a volunteer for respite."

One time, a volunteer came to the meeting to sit in on her patient's discussion. They discussed her patient first, and it lasted less than a few minutes. She was asked if she wanted to contribute anything, and she said a few words. And then they moved onto the next patient, with the facilitator saying to the volunteer that she could stay if she wanted to. The volunteer appeared very surprised at how quick it was. She had to be somewhere in an hour, and it was clear that she expected the discussion to take up a significant portion of that time. She did stay for a few minutes and then left after the next patient was discussed.

Throughout the meetings, the facilitator frequently said, “Is that everything?” to keep the meeting moving. At some points, she interrupted people, saying, “We have a huge list. We need to move on.” A possible interjection when a particular discussion seemed to be getting too long was for one of the managers to say, “Do we need to do a case conference?” Case conferences were meetings scheduled to discuss patients/families with particularly difficult or complicated issues. Only the pertinent practitioners were involved, and they were scheduled on an as-needed basis. When “case conference” was suggested, it was with an annoyed tone. The message was that the discussion was taking up too much of other people’s time. It sounded more like a reprimand than a suggestion. Most of the time, when “case conference” was mentioned, someone would say “No, we’re done.” On a few occasions, they did indeed say that such a conference was necessary, and then they moved on, implying they would schedule it after the meeting.

The managers congratulated or complimented the workers when the meetings appeared to be finished quickly. Once Red Team workers were explicitly encouraged to compete with Blue Team for speediness. At the beginning of the meeting, one of the managers said: “Not that the pressure’s on but Blue Team did 26 patients in one hour and 45 minutes.” At the end of the meeting, another manager said: “That’s it – you all did a great job. Nineteen patients in one hour and 20 minutes.” In this case, “great job” meant finishing quickly. Again we see quantity paradoxically used as a measurement of quality.



## *Documentation*

My introduction to the importance of documentation at Hometown came early in my observations. Hometown had a Joint Commission Accreditation review that ended directly before I began observing. I sat with social workers and chaplains as they watched a videotape of the reviewer's final comments to the organization. The following is an excerpt of these comments, and a piece of the conversation the practitioners had in response:

Reviewer: There is a good level of practice and sophistication at the organization, but the documentation is not as detailed as it should be. It should be relevant to patient care... If you speak with the physician or communicate with others, you need to write it down. I can see that you are sharing lots of information with each other and that's good. Yet, you must write it down or it is lost. The hospice event begins with the referral and goes through the bereavement period. You see the specific needs of the patient and family. You come up with a goal. And you intervene to make the goal. ...I can't stress enough that your work is truly within the standards of J. Comm. However, the documentation often simply wasn't there. If you do it, give yourselves credit for it. No one writes the story better than you because you lived it. So write the story.

After the tape ends, the manager turns it off. She asks for "questions, comments."

Social worker: I am assuming someone will become part of a plan...

Manager: Yes. We need to be more focused in our writing. In part, we are victims of our computer system. They make for cookie cutter reports. [The computer software program] puts people in pegs. We need to individualize plans. For example, if you choose high-risk bereavement, what is it that makes you choose it? Write it in "free text."

Social worker says she didn't know they could do that.

Manager: Yes you can, but there is something like a 52 letter limit, so it has to be brief. If you say “patient had a comfortable death,” you could write in free text something like “has visited family, children are taken care of,” whatever. (Notes 1, pp. 26-27)

In this excerpt, we see one of the consequences of being accredited by the Joint Commission: tremendous paperwork expectations. The reviewer implored them to write down everything that is relevant to patient care, telling them to “write the story.” What they write will still be just an approximation of what actually occurred, however, as Smith (1974) argues in her article “The Social Construction of Documentary Reality.” Hometown practitioners learned how to turn their interactions with patients, physicians, and each other, into a documentary reality, which then stood in for what actually happened. They were forced to subsume entire social interactions, from brief conversations to months-long relationships, into very few words.

The stories that got documented were inevitably affected by the routinization and expectations of efficiency already evident in the organization. At Hometown, for instance, when they admitted a patient, they chose from the same list of potential problems for each new patient’s care plan. As written above, they had problems that were considered more for nurses, like “pain,” “breath patterns ineffective,” “weakness/fatigue,” and “nausea/vomiting,” and there were problems that were considered more psychosocial in nature, such as “grief,” “coping difficulty individual,” and “legal issues unresolved.”

Choosing from the same problem listing for each patient gave the practitioners the chance to do a little less work in their creation of each

documentary reality, as they did not have to invent new language and descriptions each time. It was not only routinized, it was also a prime indication of the value placed on efficiency in their organization. They had set up their system of documentation so that very little free writing actually occurred. This time-saving measure served also to constrain their creativity in devising a patient's care plan and documenting what occurred. As one of the nurses said in our interview, "The nurses are more robotic because they don't have, they're not encouraged to think, and specialize a person's plan of care." This is an example of how rationalized systems impede the individuality of its members (Weber, [1947] 1964).

One of the managers told me early in my observations that "The problems are all in the computer, and then we add to them to individualize the care plan." In other words, they took the same frame and put it on every new patient, and then modified it as necessary. Yet the same manager complained above about their computer software, saying that it "puts people in pegs," and therefore did not allow for much individualization. It is evident that there was very little individualization in the construction of care plans for each patient. Instead of looking at how Hometowners may be responsible for this, however, she reified the computer system, saying that it was to blame for their documentation issues.

The problems for each patient were originally chosen by the nurse and social worker who admitted patients. But the practitioners could "close" a problem during a patient's stay if they thought it had been dealt with (or if they were no longer doing anything about it), and add new problems as they saw fit.

This was one issue about which practitioners asked for advice during team meetings. The following is a brief example of such an exchange:

Social worker: He said he's not sleeping. He's so tired. I don't know if we can do something about it.

Pharmacist: Did he say why?

Social worker: He just can't fall asleep. If he does, it's for a short period of time. I said about the ritual thing, suggested cookies and milk.

Pharmacist: Maybe a little bit of Xanax.

Social worker: Should I add a problem?

Physician: Insomnia.

Pharmacist (ignoring him): What is it – “sleeping patterns ineffective?”

Physician: What's wrong with “insomnia?”

Social worker: Because it's not in the computer.

Facilitator/manager: You have to punch it in. You can't type it.

(Notes 34, p. 45)

In this excerpt, we see a Hometown physician being taught a lesson in the routinization of documentary reality. In order for the social worker to add to this patient's care plan that he was taking a medication because he was having trouble sleeping, she had to “add” a “problem” that is “in the computer.” Therefore, she could not just call it anything she wanted. The physician suggested “insomnia,” but that would not work in their rationalized system. It had to be a term that was in their preexisting problem listing. When he asked why, the computer was

reified again, as if they were constrained by what was “in the computer.” Never mind that a human being had to put it there in the first place.

### *Medicare Regulations: Recertification*

Increased rules and regulations also indicate a rationalized workplace. At Hometown, this was shown through the powerful effects of Medicare certification on their work. Medicare regulations influenced team meetings in a number of ways, with what is called “recertification” being one of the most prominent. In order to be eligible for the Medicare Hospice Benefit, a person must be certified by his/her primary physician as well as a hospice physician as “terminally ill.” This has been defined in Medicare regulations as having six months or less to live. Patients whose care is funded by Medicare monies must be continually recertified as terminally ill, or what Hometowners called “hospice-appropriate.” If a person is with hospice for 90 days, his/her first Medicare “benefit period” comes to an end. S/he must then be recertified by both physicians as having a six months or less prognosis in order to begin the second benefit period. After another 90 days, the process happens again. Thereafter, the person must be recertified every 60 days.

There is no question that the time period “six months or less” is a social construction. One veteran employee even referred to it as such in my interview with her, when she said, “The six month prognosis is simply a figure picked by a legislator when the whole Hospice Medicare/Medicaid bill was passed. It’s not medically sounded [sic]. It was the number that was picked by Congress, to make someone quote hospice appropriate.” However, they frequently reified this

concept. This is a classic case of the Thomas theorem in action, in that government officials, auditors, and hospice practitioners defined terminally ill as six months or less to live. This definition then became consequential, not only for Hometown workers themselves, but in particular for patients and families. If a hospice patient is thought to have more than six months to live, then s/he is at risk of not being admitted to hospice at all, or later being discharged from hospice care.

Since the regulation gives ultimate authority to physicians, hospice physicians have a significant gatekeeping function in the organization. They decide whether to “recert” someone or suggest that s/he be “discharged.” However, they almost never see hospice patients. Therefore, they have to be given information from others concerning the patients’ medical status. Hometown’s consulting physicians preferred to have patients’ primary physicians give clear evidence that a patient was appropriate for hospice. This was particularly the case when the primary physician was considered “hospice savvy,” or knowledgeable about hospice-appropriateness and recertification. If not, his/her perspective was less highly valued.

The Hometown Hospice physicians got most of their information from Hometown practitioners themselves, particularly nurses. By far, the most common topic of concern in the meetings, particularly to the physicians, was whether or not the patients were appropriate for recertification. When their discussions of a patient lasted longer than a few minutes, this was usually the reason. They spent this time trying to predict something that is inherently

unpredictable: time of death. Predicting when someone will die is at best only an educated guess on the part of medical professionals. And Hometown practitioners' predictions were often wrong. Sometimes they thought that a patient was improving, and then s/he died soon after. At other times, they predicted patients would die sooner than they actually did. In such cases, they said the patient was in a "slow decline" or that someone was "in a window" or was in his/her "bonus days."

Predicting an individual patient's life expectancy is difficult to do, and they were preoccupied with the task. This was especially the case for what they call "non-oncological" patients, a category they created for all patients who did not have cancer. Cancer has always been the most common diagnosis for people who have hospice care. From the beginning of the modern hospice movement, hospice practitioners have claimed expertise in symptom management for cancer patients. But I would argue that as hospice provision of care became more rationalized, cancer has been the diagnosis of choice for another reason: they see it as offering greater predictability. From my first meeting with one of the managers of the organization, this was clear. She said that when a person with cancer was referred by a physician, it was "usually a done deal" that they would be admitted to Hometown, because it was "usually pretty advanced," and therefore, in their perspective, more predictable. But, she said, "cardiac" patients, "Alzheimer's and ALS" are difficult. She said with these folks, they may admit them and "watch them for 90 days," or the first benefit period, to see if they are

“appropriate.” They preferred cancer patients, especially advanced ones, because they felt they did not have to worry about audits from Medicare.

Once, before a team meeting began, I observed a conversation between a more veteran Hometown physician and a newly hired physician. The veteran physician said:

The non-oncological folks are tough. ...I've been looking at the guidelines, trying to update them, but there is very little literature on this. With the six month prognosis, we spend a lot of our time punting. Often, we'll see that patients dip down right before they come to us, and then they come up, but not as much. We see them after they've been hospitalized... They are fixin' to die, we get 'em home and they stabilize and then just sit there.... But some dip down and stay. You never know. (Notes 25, pp. 1-2)

Again we see that folks who do not have cancer were considered more difficult to predict than those with cancer. And we see how Hometown Hospice workers were trying to standardize the prediction, to be surer about who *really* had a six month prognosis, and who did not. What is most interesting about this excerpt, however, for my purposes, is her last sentence: “You never know.” At one and the same time, she was saying that doctors cannot know when someone is really going to die, and that the guidelines need to be updated as if then perhaps they could figure out when someone is really going to die. It is paradoxical. The difficulty, if not impossibility, of the task becomes apparent.

Their preoccupation with predictability is an indication of the powerful influence of Medicare regulations on their work. The “six months or less” stipulation was never far from their minds at the meetings. Following is an excerpt from my observations of one of the many conversations during the



meetings concerning a patient's "appropriateness." This patient's hospice diagnosis was "dementia," so she fell into the "non-oncological" category:

Nurse: Should we follow her through her next benefit period?

Facilitator/manager: I don't know. If she's clearly not appropriate, we should discharge her.

Physician and manager discuss amongst themselves for a minute.

Manager: [The physician] was just saying that if we do take dementia patients, they need to be ecog 4 [bed bound].

Physician: Unless there's something else going on like heart attack or stroke.

Nurse: Not ambulatory, not able to dress or bathe.

Physician: Dependent on all ADLs [Activities of Daily Living]. Cannot feed themselves.

Nurse: Can only speak six words or less.

Physician: One episode of infection is not a pattern. They need to have had multiple infections or foley [catheter] with UTI [Urinary Tract Infection] or in and out of the hospital.

Nurse: Or profound weight loss.

Physician: Right. They need something else. Unfortunately, each has to be looked at individually. It's not like metastatic lung cancer where you can call me up and say 'this person has metastatic lung cancer' and I can say they're appropriate. With heart patients, COPDers [Chronic Obstructive Pulmonary Disease], it's more difficult.

Facilitator/manager: So now what?

Physician: I don't know. We've signed her up... I hate to come in here and say one month and pull her out.

Pharmacist: After three months, we can.

Physician and Facilitator/manager: Oh yeah.

Physician: This is not an easy situation. Some people are clearly appropriate and some people are clearly not. Some are in the middle. ... She had a holiday decline. She's had two hospitalizations since January. Right now she's clinically stable. We'll just keep talking about her every two weeks.

...

Facilitator/manager to social worker, who has the team meeting sheet: On the sheet you should write "monitor closely for hospice-appropriateness." (Notes 9, pp. 36-38)

In this excerpt, we see how they tried to predict whether someone fit Medicare regulations for being terminal. You see from the beginning of the excerpt that "appropriate" was the shorthand code for this. The physician compared different diagnoses, saying that cancer patients are easier to predict, particularly if the patient has "metastatic" cancer (cancer that has spread to other organs or tissues in the body). Hometowners did their best to come up with criteria for appropriateness, but I will reiterate that "when someone will die" is an inherently unpredictable issue. However, with Medicare certification, they had no choice but to try to predict it.

In the excerpt above, they questioned whether the patient should even have been admitted, and they lamented having to deal with it now. They decided to keep her on, at least for the first benefit period. Again we see the influence of Medicare regulations, in that "benefit periods" and "recertification" are simply a part of the hospice language. And the last statement in the excerpt is a reminder about documentation, a crucial component of any bureaucratized organization. In this case, a social worker was told what she should write about the discussion concerning this patient on her team meeting sheet. Notice how much was missing

from their discussion in the documentary reality: “monitor closely for hospice-appropriateness.”

Following is another excerpt from a team meeting which exemplifies their preoccupation with appropriateness. This is a good example of the kinds of questions that physicians asked the nurses, in order to predict someone’s life expectancy. This patient was considered particularly difficult in that respect, and they were clearly concerned that he was with Hometown for too long, according to Medicare:

Nurse: ...His benefit period, he’s been with us over a year. What can I say about Bill? He’s up and down. He’s dying then he’s not. He’s basically stable. He has good days and bad days.

Physician: Is he bed bound?

Nurse: Yes. He looks terrible.

Social worker: He sleeps much of the time.

Physician: The wife wouldn’t let him go for a while.

Social worker: Oh yeah, she’s ready.

Physician: You know this chart is goin’ to get reviewed. So what do I say?

Nurse: ... He is appropriate so what’s the deal.

Manager: We need to show he’s continuing to decline.

Social worker: He can’t decline much more without dyin’.

Nurse: That’s exactly right. He was barely breathing today.

Social worker: Then he eats all day. She feeds him?

Nurse: He asks. He’ll have bacon and eggs.

Physician: He has to be fed, right?

Nurse: I think he does a little bit on his own. He shakes a lot.

Physician acts like he's writing, "beats the hell out of me why patient is still alive."

Several people giggle.

Chaplain: Other Hometown chaplain] is continuing support especially for [patient's wife]. The son told the wife he no longer wants [chaplain] to do the funeral. [Chaplain] said she could assert what she wants.

Social worker: She won't do that.

Pharmacist: And we talked about this before. She sees what's goin' on, and knows when it's her turn...

Social worker: Plus they [her sons] are supporting her, giving her money. She's not goin' to fight. That's just the way it is.

Chaplain: Is that part of why he's not dying? He's protecting her on some level?

Social worker: I don't know. I don't think so.

Pharmacist to nurse: The other thing you can do is go through the non-oncological form again. Document everything on there. He should be dead. It's a useful tool to go back to.

Physician: That's not a bad idea. It's an approved tool and it says what it says. That's the start of an argument that we followed procedures properly and got a funny result. If it happens...

Nurse: He's declining. That's very clear. It's just gradual.

Pharmacist: That's the way to use the rules to protect us. Go through the whole thing again. He's goin' to meet it in spades.

(Notes 18, pp. 69-71)

In this excerpt, a lot is going on. Again, we have a patient who did not have cancer. (In this case, he had Chronic Obstructive Pulmonary Disease). The physician wanted to know whether the patient was bed-bound and needed to be fed. He asked these questions as if he wanted an answer in the affirmative. This is an irony in hospice work when Medicare reimbursement is involved:

Hometown workers often sounded as if they *wanted* patients to be declining, rather than improving, because then they did not have to worry about files being audited, or questions of appropriateness.

In the excerpt we also see the difficulty with physicians being the ultimate authorities concerning recertification, when they did not see the patients. The practitioners who had seen this patient said he was practically dead, although he had moments of improvement. The physician's main concern was that the patient's chart was going to be "reviewed," and he needed something to write down. Again we see the importance of documentation in this work. He felt he had to write something that proved this man was going to die soon. And what he wrote must be strictly medical in nature. This was why the nurse was asked to fill out yet another form about this patient, a form listing Medicare-accepted criteria that qualified non-cancer patients as "appropriate." The several statements about the patient's family, in which the social worker and chaplain were trying to predict death based on psychosocial factors, are good examples of how the predictive factors they used were not always medical. However, these were not useful to the physician, who had to follow the dominant biomedical model when

predicting appropriateness. This had everything to do with the possibility of an audit or Medicare review.

I will include one final excerpt of an appropriateness discussion, although there are dozens from which to choose:

Physician: Is she still appropriate?

Nurse: If you look, at the end [she points to the binder], there's a note [from the doctor]. I am questioning her appropriateness of her continued hospice.

Facilitator/manager: When's her next recert?

Nurse: Is it on the 8<sup>th</sup>? It's coming up.

Physician: November 6<sup>th</sup>. We just recerted her 8/9. Can we decert?

Facilitator/manager: Yes. We don't have to keep her three months.

...

Physician reads a note from the doctor: See her in three months. Continues to be Hospice appropriate.

Nurse: The only thing she has is incontinence.

Physician: That's neurological.

Nurse: Exactly.

Facilitator/manager: She could be in a window.

Pharmacist: A long window.

Nurse: I go two times a month. ... I check her med-box.

Physician: We get paid \$100 a day whether we're seeing her or not, right?

Facilitator/manager: Yes, but if she's not appropriate, it's fraud.

Physician smiles and people giggle.

Facilitator/manager continues: They could decline payment.  
In the audit, if they see she's not appropriate.  
(Notes 26, pp. 32-34)

In this excerpt, we again see the difficulty of accurate prediction. We also see how the hospice physician had to count on other people's assessments to make a decision concerning a patient's appropriateness. Although the primary physician said the patient was appropriate, the hospice nurse herself disagreed. The physician's assessment would generally carry more weight, simply because his expertise is considered more legitimate. But in hospice, at least at Hometown, a physician's assessment was often suspect unless they considered him to be hospice savvy. In this case, the physician's note said that he did not have to see this patient again for three months, a relatively long time for a supposedly terminal patient. Hometown practitioners had indicated that they consider this a red flag that the physician was not clear on the "appropriateness" factor. Therefore, the primary physician's opinion seemed less important. The hospice physician appeared to be leaning toward the nurse's perspective in this case.

In this excerpt, we also see an example of the facilitator and pharmacist using hospice lingo when they said the patient might be "in a window." This meant that she was appropriate but just did not appear to be at that time. She was doing well, but it was temporary. This phrase allowed them to be indecisive; it allowed them to say that a patient appeared appropriate but did not appear appropriate at the same time. In that sense, it was convenient.

Continuing with the excerpt, the nurse then continued to make her case that the patient was not appropriate, by invoking another staple issue of hospice

work: frequency of visits. She said how infrequently the patient needed nursing visits. Two times a month is the fewest frequency of visits allowed for a Hometown nurse. When a patient was seen to need this amount or fewer visits, this was often used as “evidence” that a patient should or could be discharged from services.

At the end of the excerpt, we hear the Medicare per diem payment system invoked. Medicare monies were paid to Hometown Hospice for each patient that has Medicare as his/her payer source. Hometown (and other hospice organizations) get paid a certain amount per patient per day regardless of what the patient actually costs. Hometowners were all aware that they lose money on some patients and gain money on others. And though the former issue got invoked in the meetings, phrased in terms of cost consciousness, this was the only time I heard the latter explicitly mentioned in a meeting. Though they knew it is possible to make money from patients, this physician learned here that it was not appropriate to say so explicitly (at least not in a semi-public setting such as a team meeting), when the facilitator said it would be “fraud” to keep a patient whom they know to be inappropriate for hospice. Medicare monies are not provided as direct reimbursed costs for specific items, but there are restrictions as to how the money should be spent. The practitioners knew that Medicare could “decline payment” for patients that were not legitimately considered hospice-appropriate.

In the end, we see in this excerpt that the issue was not really resolved. This, too, was typical. Often, after many minutes of going around and around,



they did not appear to come to a real decision on a particular patient's issue before the next patient got introduced in the meeting.

*Medicare Regulations: No Aggressive Treatment*

Medicare's "six months or less" stipulation was not the only influence on team meeting discussions. The regulations say that when patients sign up with the Medicare Hospice Benefit, they choose "hospice care...rather than curative treatment." (*National Hospice Foundation: The Medicare Hospice Benefit*, 2000). Hometown Hospice had to be vigilant about their Medicare patients at all times, making sure that they did not receive any treatment which might be considered "curative" (or what Hometowners called "aggressive") in nature. This is more ambiguous than it may sound.

Hometowners typically counterpose "palliative" and "aggressive" treatment, with the former being acceptable for hospice patients, and the latter being unacceptable. But some treatments can be considered either palliative or aggressive, and this is where things get difficult. The practitioners themselves were often unclear as to whether or not certain treatment was "hospice appropriate," meaning that it fit with Medicare guidelines. Again we see that with rationalization, the very definition of who and what is "appropriate" for hospice was modified to fit bureaucratic regulations. And just as they spent significant time in the meetings attempting to determine whether patients fit the "six months or less" rule, Hometowners also spent time trying to figure out whether patients' physicians were following the "no curative treatment" rule. The two of these rules together comprise Hometown's concept of "hospice appropriateness."

A few excerpts of such conversations may illuminate the importance of Medicare regulations, and the frustration Hometowners often showed with the ambiguity of enacting their terms. Radiation and chemotherapy, as examples, are the most frequent treatments given to cancer patients in conventional medicine. Both of these treatments are typically used to kill off cancer cells, in efforts to achieve remission. In hospice, the goal of remission would be considered “curative” and therefore not appropriate under Medicare guidelines. However, chemo and radiation can also be used for palliative reasons, and therefore be considered hospice appropriate. In the following excerpt, the workers attempted to determine whether a patient’s treatment was appropriate or not:

Nurse: Every day she goes to UNC for palliative radiation. As far as I can determine, she’s scheduled all the way through October.

Physician: Wow, at 86.

Social worker: That’s what I said – 86.

Faciliator/manager: Are we paying for this?

Nurse: I assume. It’s palliative.

Social worker: Also the toll on the patient.

Physician: Is it helpful?

Nurse: Violet, the daughter, they told her it’s shrinking. You can feel the mass – they told her it was working. They said if she’d not have radiation, she’d have a terrible time.

Facilitator/manager huffs: Yeah, she’d die.

Nurse: ... The patient is reporting that she’s feeling better.

Physician: It sounds like a difficult situation.

Facilitator/manager reports to the pharmacist, who has just returned to the room, that this is a patient getting daily radiation at 86, through October.

Nurse: She has time off.

Pharmacist: This is active treatment to shrink the tumor. There's no way to justify that. It's wonderful if it's helping her, but.

Facilitator/manager: Is it palliative?

Pharmacist: Palliative and symptom management are two different things. It's palliative. But we'd get creamed by hospice Medicare for this.

Facilitator/manager: Were you here when [other physician] was talking about this – whether it's systemic or directed to the tumor. If it's tumor shrinkage, then it's too aggressive.

Pharmacist says something I miss.

Nurse: Eight cycles they have scheduled.

Physician asks how long she's been going.

Nurse: I think three weeks.

Pharmacist: That's very active therapy.

Physician: That's not palliative.

Pharmacist: That's insane, quite frankly. There are a lot of things people can do to extend life that won't cure the cancer. In the physician's mind it's palliative, to help the patient, but that's not how it goes.

Facilitator/manager: Postponing the inevitable.

Physician: So it's life-prolonging.

Other nurse: But we didn't know that at admit.

Pharmacist: I don't know.

Nurse: I think we did.

Facilitator/manager: We need to approach the family; she's not appropriate at this time.  
(Notes 26, pp. 40-43)

In this excerpt, we see how they struggled with defining the term “palliative radiation.” The nurse originally said that this was what the patient was receiving, assuming that because the treatment had been called “palliative,” that made it okay, and that they would pay for it. But as they talked, their certainty of this was questioned. When the physician asked if the radiation had been “helpful,” for instance, the nurse responded that the cancer mass was “shrinking,” but also that “she’s feeling better.” The former indicates curative treatment while the latter illustrates the goal of palliative treatment. The pharmacist then said that this was “active treatment to shrink the tumor,” which is another way of saying that it was curative treatment, and therefore not hospice appropriate. Later, she said “it’s palliative,” which would indicate hospice appropriateness, but that they would “get creamed” by Medicare for subsidizing it. Still later, the physician said “that’s not palliative.” They contradicted themselves throughout the conversation.

The physician, the facilitator/manager, and the pharmacist did come to an agreement at the end of the excerpt that the treatment was “life-prolonging,” and therefore not hospice appropriate. In the last sentence, the facilitator used the proverbial “we” to mean that the nurse and social worker assigned to the patient had to tell the family that the radiation made her ineligible for hospice care. So the folks in the meeting who rarely saw patients agreed that the patient was not

hospice appropriate, but the necessary face-to-face conversation with the patient and family fell to the nurse and social worker.

And this was not actually the end of this conversation. This patient remained a Hometown patient, and continued to get radiation treatment. Two weeks later, she was brought up again in the team meeting:

Physician: The last note says she's no longer hospice-appropriate.

Nurse: She'd been taking palliative radiation for symptoms of pain. She's on a three week cycle. She's ready to start the next cycle on Monday. She'll go every day to UNC, and then she'll be off another two weeks. I called the doctor.... I explained to him about the palliative radiation and that we need more information. Monday she will get reassessed. I don't know for sure till she goes in.

Physician: When we talked two weeks ago, we discussed that the radiation would prolong life.

Nurse: I had a long discussion with the family. Their understanding was that it's for pain. They don't want to continue the treatments if it's not appropriate. They have to get her to UNC and back.

Physician: How is her pain?

Nurse: She has no pain. She didn't on admission... She's got disease – the nodules in her vagina are just tremendous. They're right there. I was not comfortable discharging her because I was not able to talk with the doctor. After the family said they too didn't want to continue the radiation...

Physician: If she's not having pain, radiation therapy excludes her from hospice. They could say radiation therapies have prevented her from becoming symptomatic. All therapy occurs to prevent symptoms, to prevent death.

Nurse: We did admit her. And now we're changing our tune. That's the big issue.

Social worker: The family very much wants hospice. They are using our services appropriately.

Nurse to Physician: Personally I think you need to talk to Dr.--  
---... She'll go back Monday and she might not get more radiation. Should we discharge her without knowing?

Physician: No.  
(Notes 28, pp. 38-40)

In this excerpt, we see that “hospice-appropriate” was again used to mean withdrawing from the use of aggressive treatment, and not just having six months or less to live. This time the nurse elaborated on “palliative radiation,” saying it was for “symptoms of pain.” Except it turns out that the patient had “no pain,” and “didn’t on admission” to Hometown. The physician made the statement, “If she’s not having pain, radiation therapy excludes her from hospice.” He was arguing here that radiation can only be used to control pain, and not for other purposes. This constituted his definition of palliative. However, he then said that “all therapy occurs...to prevent death.” So he essentially said that radiation therapy is never solely palliative, because it is always curative, and therefore not hospice appropriate. So in a short span he said that radiation used to control pain was okay, and that radiation could never be used only to control pain. This was yet another indication of the confusion they had with these issues.

We also see how consequential Medicare regulations are, in that this patient and family, who “very much want[ed] hospice,” were at risk for being discharged from services. They were being forced to choose between radiation treatment, which the patient was getting upon admission, and hospice care, which the family had come to depend upon. The nurse, who was asked to deal with

these issues the last time the patient was discussed, put the impetus on the physician instead. This was just one of many occasions where practitioners showed they liked to avoid having appropriateness conversations with patients/families and primary physicians.

The importance of Medicare regulations, and the ambiguity of enacting their “no curative treatment” rule, can be solidified with one final example of a discussion concerning aggressive treatment, and whether it was appropriate or not:

Manager: ...Treatment justification: doctor has him on Prolidimide 50 milligrams - 4 tablets one week with the goal of 8 tablets a week. There has been a lot of discussion, he's had blood transfusions. We sent over a treatment justification and what's going on with him. She [pharmacist] sent a packet of information, saying to do this for one month. He is declining from what I'm hearing.

Pharmacist: I had a real problem with that, but it's true that it could possibly decrease the need for transfusions. But if he responds, we're discharging him. That's an active therapy to treat myelodysplasia. It is cheaper, though. It's \$1200 a month, while transfusions are \$1800 each. It's cheaper to us. But it's a treatment. If it works...

Facilitator/manager: If he's treating him with something, shouldn't we discharge him regardless of whether it works or not?

Pharmacist: He was getting transfusions and we said that was okay. We can't say yes to the transfusions, and say no to something that might decrease the need for the transfusions. But if the Prolidimide helps... It was a catch-22.

Physician: It's a question of intent.

Pharmacist: It is intent - one of those dual things that we can't sort out. Without the transfusions, he'd have died. Without them he's so short of breath that he's miserable. In the

material it says that “this may decrease the need for transfusions” in black and white.

Manager: The other issue, wasn't he the one? He drives around. He said, when he can't get out, he'll stop it.

Pharmacist: Right. [Nurse] wanted a case conference. The purpose in this was fuzzy to me. I don't know what his wants are. .... He probably shouldn't have gone to hospice.

Facilitator/manager: He was put on prematurely. They're still not using - he has minimal nurse support, no aide, no volunteer, no chaplain.

Pharmacist: But lots of pharmaceutical support. So the daily minimum is covering him.

Physician: He's not declining.

Pharmacist: He's weaker considerably since admission.

Physician: The national organization should have help for situations like this.

Pharmacist: This is an area that no one knows how to approach. It's a gray area that no one pays for.

Social worker: Case conference! She smiles.

Manager: He has COPD, heart problems.

Pharmacist: I wouldn't disagree with a case conference.

Manager: When [his nurse] is here to discuss him.

(Notes 9, pp. 14-15)

At the beginning of this excerpt, the manager went through this patient's problem listing. “Treatment justification” was one of the problems they used, for patients who were receiving treatment or medication that may be questionable to Medicare for one reason or another. In this case, they questioned a medication. This medication, though considered “active therapy” (and therefore not hospice



appropriate), was said to reduce the need for blood transfusions, which this patient was receiving. Blood transfusions were an example of a treatment that could be considered aggressive or palliative at Hometown, depending on the situation. In this case, the pharmacist suggested that without the transfusions “he’d have died,” which implied that they were a curative treatment, but then she said that the transfusions helped with shortness of breath. At Hometown, shortness of breath was a “symptom” and therefore, she was implicitly arguing that these transfusions were used for “symptom management,” an acceptable and hospice appropriate goal.

So though the hard line was that active treatment is not hospice appropriate, they got themselves in a tough situation in this case, by saying that the medication was okay. It turns out that other factors, such as cost and “intent,” can enter the picture. Cost consciousness was invoked here, in that the contested treatment was actually cheaper than the transfusions for which it may have been reducing the need. They knew that in a rationalized system such as their own, lowering cost was not bad. Also, they were less concerned about the treatment since the patient was not using up money with other services, so the Medicare “per diem [was] covering him.”

When they said that “it’s a question of intent,” this is a strong indication of how they spent time in these meetings attempting to interpret Medicare regulations concerning what was hospice appropriate and what was not. Hometowners knew that choosing “hospice care rather than curative treatment” was not that cut and dried. In this situation, they said if this patient’s physician’s

sole intent in prescribing the medication was reducing the patient's need for blood transfusions (a questionable treatment itself), then that was hospice appropriate. If the intent of prescribing the medication was to treat the disease, then it was not. But they also said that if the medication happens to help with the disease, then regardless of how it was intended, the patient must be discharged from hospice services. If the medication did not work, then regardless of how it was intended, it was okay. So was it the intent, or the outcome of the medication that they were concerned about? That is unclear. As medical professionals, they must have known that regardless of the intent, any treatment may keep people alive longer, even very slightly, than they otherwise would have lived, and therefore could be considered "curative."

The point is that Hometown practitioners were constrained in whether or not they allowed an individual patient a particular type of treatment, because of Medicare regulations. The ambiguity in enacting the guidelines and the inherent unpredictability of death combined to confuse and frustrate Hometowners. These factors also meant that time was spent during the meetings answering the question: "Are we following Medicare guidelines concerning the six months or less prognosis, and no curative treatment?" This was time that could have been spent answering the question: "Are we following the hospice philosophy of compassionate, holistic, and individualized, care for the dying?"

And again, consider the actual patients and families who were also caught in this fray. Most Hometown patients' services were paid for by the Hospice Medicare Benefit and therefore they were affected by Medicare regulations.

These patients got dependent upon hospice services, some very quickly. If they improved, or did not sufficiently decline while in hospice care, they risked being discharged. For many, this meant losing a significant proportion of the general care they were receiving. Without Medicare's necessity of showing sufficient and constant decline, patients and families could count on continuing hospice care. And Hometown practitioners would not have to worry about having "discharge" conversations with their patients and families.

The rule concerning no curative treatment also had consequences for patients and their families. Treatment decisions for people with terminal illnesses have many facets. People must consider the advantages and disadvantages of treatment, what they will gain and what they will lose by deciding to undergo or forgo treatment. For patients at Medicare-certified hospices, the decision becomes even more complex, because patients risk another loss if they choose certain types of treatment: their hospice care. Medicare regulations concerning treatment are difficult enough to enact that hospice medical professionals have to debate them. So the average person electing hospice care and Medicare coverage cannot be expected to be clear on the regulations. Hospice patients are often forced to choose between treatment that may make them feel better temporarily or help them live just a little bit longer (and therefore may be defined as "curative"), and hospice care. This forced choice would simply not exist without Medicare regulations.

*An Addendum: The Irrationality of Rationality*

Ritzer (2000) discusses “the irrationality of rationality,” using it as a blanket term for all of the negative aspects of rationality, as well as the ways in which rational systems spawn developments that are the opposite of rationality. In the team meetings I observed, there were clearly elements of irrationality. For instance, the practitioners often repeated themselves from one meeting to the next. Hometowners repeated particular stories about patients, their predictions of what would happen with them, and their views on the patients’ situations. Repetition in meetings is clearly inefficient. However, no one ever mentioned it as a problem. In fact, I do not think that people often noticed how repetitive the meetings were.

This may be due to the fact that, in another example of irrationality, at any given moment, very few people in attendance were actually listening to the speaker. As one person spoke, most others were typically busy writing something. I heard several workers say they used the team meetings as a time to catch up on their own paperwork. The team meeting sheets themselves also needed to be filled out for each patient at each meeting. And I observed several workers writing sympathy cards during the meetings. In addition, there were often side conversations going on, where two workers whispered to each other for several minutes.

As a result, whoever was speaking usually looked down at her papers while she spoke, or looked at no one in particular. With most others writing or chatting, there were few others with whom one could make eye contact. I noticed a pattern that when one person spoke about a patient, the other workers visiting

that patient usually paid attention. The managers usually appeared to be listening as well, except when they left the room for a phone call or an “emergency.”

When a physician was in attendance, s/he would be writing at some points and actively listening at others. Physicians paid more attention to the nurses’ reports than reports from others, however.

The workers frequently repeated themselves within the same meeting, when important points were made that someone needed to hear but missed. And only once did a worker say, “Is anybody listening?” because of all the commotion in the room. She then said, “I’m sorry. It’s just so busy in here.” There were many points where people showed in their body language that they were wondering this themselves, but she was the only one in nine months of observation who asked. Her apology shows how non-normative it was to question whether anyone in the room was listening to you, even though that was arguably one of the main points of the meetings.

In interviews, several workers shared their thoughts on the team meetings. Two interviewees in particular indicated irrational elements of the meetings. One nurse complained that the meetings were “not effective;” she lamented that “no one’s listening” in the meetings. She then rhetorically asked me, “So how do you internalize that as a nurse?” When I responded, “I don’t know,” she went on, “It is horrible. I dread team days.” She recognized the irrationality of a meeting where people do not listen to each other, and though she had spoken up about some of her complaints, the meeting structure had not changed.

Another Hometown, this time a social worker, also discussed the irrationality of team meetings with me. After we both agreed that they felt “rushed,” she said,

You know you try to say the least that you can ‘cause nobody really wants to hear it anyway.

Molly: Mmhmm, so that’s how you’re feeling when...?

Colleen (interrupting): Yeah, that’s how I feel. Definitely.

Molly: Yeah. But I’m wondering though, would you want to have these long meetings?

Colleen: I, for me, I feel like the communication at least personally that I’ve had with my, that I’ve always had with the nurses that I worked with, and the volunteers, usually that’s not necessary. ... You know, as a rule I think we communicate really well. It’s not like we wait till “team” to talk about something. (Colleen, pp. 18-19)

And later, when I asked her about the purpose of the meetings, she said, “You know, the goal is you have to fill out the care plan.” Here, she noted both the expectation of efficiency and the paperwork requirement at Hometown, a rationalized setting. She, too, did not feel that people were listening to her, and she said little as a result. She said that the meetings were essentially pointless, except to fill a bureaucratic requirement to meet and write down what people said. This epitomizes what Ritzer (2000) described as the irrationality of rationality.

### **Rationalization and the Provision of Care**

I have argued that though the hospice movement arose in opposition to bureaucratized care of the dying, hospice itself went through a process of rationalization in a relatively short period of time. I have illustrated this rationalization by showing the significance of routinization, efficiency,

documentation, and rules and regulations for one hospice organization, Hometown Hospice. I use observation data from practitioner discussions about patients, in order to do so. Throughout, I have discussed some of the consequences of these factors for those involved. Observing only the practitioners in discussions with each other has drawbacks as well as advantages. Since I did not observe hospice workers interact with their patients, it would go beyond my data to argue that the care that they give is as rationalized as their team discussions. However I can make some initial connections between what I observed and their actual caregiving.

One of the most significant factors in Hometown's provision of hospice care was its census, or number of patients receiving their care at any point in time. Though the number fluctuated from day to day, with patients dying and being admitted, Hometown practitioners kept track of the approximate number at all times. As I discussed above, their census had grown substantially in the last fifteen years to about 100, more than doubling the census prior to Medicare certification. During the time I was observing, Hometown hired a new executive director whose primary goal was to increase the census to at least 200 by the next year. He was not the only one who encouraged high numbers. On several occasions, I heard managers lament that the census was "dropping" or "getting low."

An increasing census is clearly related to the process of rationalization. As numbers increase, rationalization becomes more likely and more useful. And as an organization becomes more highly rationalized, growth appears more and

more necessary. The executive director and the managers at Hometown kept track of the census for many reasons. First and foremost, their funding (or “hard” money) was greatly dependent upon their census. More patients meant more money; fewer patients meant less money. An increasing census also meant legitimation for the organization, as well as bragging rights in the competitive market. I read several newsletter articles posted on Hometown’s bulletin boards in which authors predicted a second hospice for this particular county. Increased competition, or the threat of it, lead to a greater push to woo terminally ill patients to Hometown. One of the new executive director’s foci, then, was to increase outreach and advertising to the community, in an effort to augment Hometown’s census in the near future.

Not everyone at Hometown wanted a higher census, however, because increasing the census was seen as tantamount to increasing practitioners’ number of patients. I observed a nurses’ meeting with the executive director toward the middle of my tenure at the organization. During that meeting, several of the nurses expressed concern that they had too many patients in their caseloads. For example, one nurse said, “You know I hear a census of 200 and that’s great and all but we’re just keeping it going as it is. We have our fingers in a lot of dikes now. I don’t know if we can manage much more.” She and several other full-timers expressed feeling overwhelmed at their amount of work.

The nurses made several comments that related to both the census and their relatively large caseloads. The following excerpt from the meeting is illustrative:



Nurse 1: I've had as much as 14 [patients] at a time, and it seems like the quality suffers. With managing the symptoms, all the calling.

Nurse 2: My patients don't suffer. My family suffers. Seeing 4 patients - that's a ten hour day, and that's without lunch.

Executive director: No one expects you to work ten hour days.

...

Nurse 1: I think there should be a cap at 10 patients.

Nurse 3: I don't think you can say number of patients. Some are once a day, some once a week.

Executive director: I think sometimes you're making more visits than you need to make. You may be so conscientious that you may be making more visits than the patients require. Of course you want to give good care but you don't need to make visits beyond what the patients need.

(Notes 21, p. 37, 45)

In this excerpt, the first nurse opposed the common theme among management, that high quantity meant high quality. She was concerned that having more patients diminished her quality of care. Other Hometown workers had made similar arguments to myself and to each other, but this was a risky statement to make to an authority figure. Not only did it imply that the speaker could not handle the work, it was almost an admission that she had shortchanged patients. This may be the reason she did not have more support for her statement. The next nurse agreed that she had too large of a caseload as well, but instead of implicating the quality of her caregiving, she said that her "family suffer[ed]." This statement allowed her to complain without potentially making herself look bad in the eyes of the executive director.

In the executive director's response to the nurses' concerns, he invoked the nurses' number of visits. Typically, an increase in a nurse's caseload meant

an exponential increase in the number of visits she had to make. It was the Hometown admissions nurse's job to decide nurse frequency of visits when she admitted new patients, and most patients were scheduled to be seen at least twice a week. In an attempt at a response to the nurses' expression of feeling overwhelmed, the executive director suggested that nurses visit patients less often. In other words, instead of agreeing with the nurses that they should never feel that they had too many patients to do a good job, he instead almost encouraged them to be less "conscientious." Rather than guaranteeing that their quantity of patients would never get so high that they might be concerned about their quality of care, he eschewed their concern by invoking the quantity of visits that they ostensibly chose to make. In this way, he was able to maintain his support for an increasing census while at the same time not offering any real changes to help his seemingly overworked nursing staff.

Hometown nurses (and social workers as well) argued throughout my tenure there, that the size of their caseloads affected the care they were able to provide. This was partly because of the number of visits they had to make. The logic was that the more patients they had, the more visits they had to make, and the less likely they would be able to fulfill each patient's individual needs within a 40-hour work week. As a social worker said in an informal conversation with me, "I have 21 patients right now. I'm supposed to be capped at 22. I asked [a manager] 'is someone going to cap me?' She said probably not. It will get to a point where I physically will not be able to do it all. I cannot see 21 patients

every week, you know?” They felt that seeing all of their patients as often as they needed to be seen was at points impossible.

Another piece of this was the amount of paperwork that they needed to do for each patient. Again, the more patients they had, the more paperwork they needed to fill out, and the less time they would have to actually spend time with patients. More likely, they chose to see patients instead of doing paperwork. In these cases, they received “deficiency reports” from management, saying that they were behind in getting something in. Nurses and social workers frequently complained that they had too much paperwork. In reference to the bureaucratization of their work, one nurse at the meeting with the executive director commented, ““With J. Co [Joint Commission on Accreditation of Hospitals], Medicare, it’s more than what we can handle.” Hometown workers felt overwhelmed with more patients not only because of the number of visits required of them, but also because of the increase in the necessary paperwork.

I have shown that Hometown workers generally appeared to see a positive relationship between how often they saw and spoke with patients, and the level of care the patients received. Interestingly, however, they contradicted this sentiment by complaining about the length of time they had to stay with some patients. Before I began observing at Hometown, I had imagined that hospice workers spent upwards of several hours with patients on a regular basis. In fact, I was given several indications of how short Hometown practitioners’ visits could actually be. I peeked at one nurse’s daily log, for example, and her visits averaged thirty minutes apiece. Another nurse showed me her daily log with

pride, saying that she had visited four patients in less than four hours (including driving time). When I appeared surprised, she said, “Some patients take ten minutes. Some take an hour and a half.” She suggested the two time amounts as if they were ends on a continuum.

An excerpt from a team meeting discussion about a patient who required “lengthy” visits corroborates this:

Nurse: It’s always a very lengthy visit with [the patient]. The last time I went she was in the bathroom and needed help. And she’s as slow as an inch worm. I’m never there less than an hour.

Social worker: And she always wants me to stay. You have to set limits with her.

Chaplain: I do the timing so that [the nurse’s aide] comes after me.

Nurse: Oh, you’re smart. I was thinking I could say I’m getting a page and that I’m needed.

Pharmacist: An emergency. ... We’ve done that before.

Nurse: I might have to do that.  
(Notes 20, p. 9)

In this excerpt, the nurse, social worker, and chaplain for a particular patient agreed that the patient wanted them to stay with her longer than they wished. We get an indication for what was considered “too long,” because the nurse said that she’s “never there less than an hour.” So though they implied (and sometimes outright stated) that the care their patients received was negatively affected by having too many patients, this argument was questionable when they complained about having to spend actual time with their patients. For a more congruent argument, they would have had to comment that their visits were cut too short

because of bureaucratic constraints. Instead they complained that their visits were at times too long.

Regardless of Hometown workers' perspectives on these issues, the point remains that their care could be affected by the census of the organization, and the size of their caseloads. Members of management paradoxically used quantity as a measurement of quality, by saying that a higher census was tantamount to better care. But that is a dubious argument. A higher census means that more people would be receiving hospice care, but the quality of that care is not guaranteed. If increasing the census means increasing the size of practitioners' caseloads (and it had thus far at Hometown), then that suggests a rationalization of not only the team meetings, but also of the actual caregiving itself. The more patients each worker has to see, the more they will be encouraged to streamline their care and shorten the time they spend with each patient. The more routinized and efficient the caregiving, the less individualized it necessarily becomes. In this way, rationalization went beyond their discussions of patients; it affected their treatment of patients as well.

### **Conclusion**

The modern hospice movement has a short history, but it has been in constant flux since its charismatic beginnings. Though the early leaders sought alternatives to what they saw as the overly bureaucratized care of the dying, the growth of the movement led some to be concerned about the lack of official standards of hospice care. And though the early practitioners depended solely on community donations and grants to offer care, more and more felt financial

difficulties looming. In turn, hospice practitioners began seeking legitimation and stability through Medicare certification and the option of accreditation. Before long, the provision of hospice care became dependent on these developments. Their influence on hospice work cannot be overstated.

Hometown Hospice, the organization of study here, has been particularly affected by the rationalization of hospice work. In this chapter, I show how the expectations of efficiency, increasing routinization, the importance of documentation, and the regulations associated with Medicare certification are ever-present for Hometowners. I have discussed the benefits as well as the unintended consequences of these aspects of rationality for those involved. Hometown represents how the provision of hospice care has changed over time. These changes threaten what made hospice special in the first place – individualized care for the dying. And with an escalating census, and growing complexity in the division of labor of the organization, all signs point to increased rationality in the future.

In the next chapter, I further discuss the consequences of the rationalization of an originally holistic, individualized ideal. I discuss how, in this process, Hometown Hospice was forced to attempt a combination of two very different health care models in practice. The resulting contradictory guidance offered to the front-line workers caused tension and unease with which they were left to deal, on their own.

## **Chapter 3**

### **Mixed Messages for Front-Line Workers:**

#### **Hometown Hospice's Attempts at Merging Two Disparate Health Care Models**

At Hometown Hospice, workers from different orientations provided services to the terminally ill and their families. Some of the workers had primarily medical backgrounds, while others' training focused on supportive counseling and support. These workers were put together to comfort terminally ill patients and support their families, but these were often difficult to achieve.

I argue here that one reason for this difficulty was that Hometowners were trying to follow two contrasting models of treatment for patients and their families: the dominant medical model and the psychosocial model. As I show in the last chapter, Hometown Hospice had gone through a process of rationalization over time. This primarily involved the process of certification to receive Medicare monies, and accreditation by the Joint Commission on the Accreditation of Hospitals. And to a large extent, the Medicare regulations set forth by the federal government and the acceptable criteria for accreditation are consistent with the dominant medical model. To that extent, Hometowners were forced to follow the dominant medical model in practice, whether they preferred to or not.

However, the original hospice ideals lend themselves to a different model that professional practitioners can use when working with patients. This has been called the "psychosocial" model. The hospice philosophy – patient-centered

care for the terminally ill that is palliative, holistic, and provided by members of an interdisciplinary team – conforms well to the ideal-typical psychosocial model. Therefore, hospice practitioners attempt to follow this model, to whatever extent they can, in practice. Hometown Hospice workers were no different.

As I demonstrate in this chapter, the two models differ to the point of contradicting each other. Yet the Hometown front-line workers who were present at the team meetings were expected to simultaneously follow both models in their day-to-day work. They received mixed messages about which model they should follow, when. As I show in this chapter, the lack of clear guidance benefited management in various ways. But without clear expectations, the front-line workers often felt unsure if they had fully accomplished their jobs. Though they did not explicitly use the language of models, I argue that this conceptual framework helps to explain the unease the workers frequently displayed about how well they were doing their jobs.

### **The Contrasting Components of Two Models of Patient Treatment**

#### *Components of the Dominant Medical Model*

The medical model (also called the biomedical model) is the dominant model of practice in conventional medicine. In the ideal-typical version of this model, there is a hierarchical distribution of authority among specialized medical experts. Doctors are at the top of the hierarchy, while nurses and other health care workers follow the orders given by physicians (Cancian and Oliker 2000; Lorber 1997; Meyerson 1994). Medical professionals are trained in specialist services within a strict division of labor (Meyerson 1994). They use the technological



tools of their specialized trade (James 1992a). And in this model, patients do as they are told. Patients take on a passive role while physicians either decide what is best for their patients or guide them to cooperate with their orders (Weitz and Sullivan 1990). Szasz and Hollender (1955) refer to these as the “activity-passivity” and “guidance-cooperation” models of the doctor-patient relationship.

In the medical model, individuals’ physical attributes are given priority. Physicians diagnose diseases in individuals’ bodies and define diseases as having physiological origins. Any connections between physical, social and emotional factors are ignored (Cancian and Oliker 2000; Weitz and Sullivan 1990). Bodily problems require physical treatment by medical experts (James 1992a). These experts are called on to control, treat, and ultimately cure individual pathologies (Meyerson 1994). The goal is to avoid death if at all possible (Cancian and Oliker 2000).

For the purposes of fixing people’s problems, “medicine relies on science as its epistemological core” (Meyerson 1994, 645). Health care professionals are trained in a scientific model of disease. They prize objectivity, using scientific tools and technology to claim objectivity in their measurements to solve disease. (The fact that they need to interpret results – a sign of subjectivity – is ignored (Lorber 1997)). In the process of objectively fixing disease, patients themselves are transformed into “complex intellectual puzzle(s)” (Smith and Kleinman 1989, 60). Scientific problem-solving encourages, if not requires, distancing from the humanness of patients (Meyerson 1994; James 1992b). Medical professionals are

trained to see patients as bundles of physical attributes, some of which need fixing through their expertise.

The dominant medical model requires emotional distance from patients. This has been referred to as “affective neutrality” (Parsons 1951). Emotional involvement with individual patients is proscribed. Instead, medical practitioners should have a generalized and impartial compassion for patients’ problems (Daniels 1960). This is said to encourage medical professionals to treat patients alike, another piece of the medical model (Smith and Kleinman 1989). Treating patients objectively, as puzzles to be solved, fits with detachment from the patients as people. According to this model, emotional involvement impedes objectivity, therefore hindering practitioners’ abilities to do their jobs (Haas and Shaffir 1977). Concern for patients as individuals may lead not only to differential treatment of patients but also burnout on the part of the practitioner. Therefore, it is discouraged.

#### *Components of the Psychosocial Model*

There is another model that professional practitioners can use when working with patients (or clients). This has been called the “psychosocial” model, one consistent with a social work orientation (Meyerson 1994). In the ideal-typical version of this model, multidisciplinary teams provide general services to patients. Rather than being highly specialized, psychosocial practice is interdisciplinary, with power and responsibility dispersed among varied professionals.

In the psychosocial model, patients play an active role in their treatment. An important aspect of this model is a belief in patients' "self-determination." This entails giving as much control to patients as possible, to define their own conditions and treatments. "Social work training emphasizes the importance of helping people help themselves and helping them change, accept, or adapt to their social situation" (Meyerson 1994, 644). Rather than attempt to control the care that they give to patients, those following a psychosocial model are encouraged to relinquish control to their patients (Weitz and Sullivan 1990). In Szasz and Hollender's (1955) conceptual approach, this is referred to as "the model of mutual participation."

The psychosocial model encourages a holistic approach to caring for patients. Using this model, practitioners see connections among patients' social, emotional, spiritual, and physical experiences. In fact, patients' conditions are often seen as caused by social phenomena, rather than physiological factors. A holistic approach to health care necessitates a more complicated view of patients' conditions than one focusing solely on physical factors. The psychosocial model rejects the "monolithic fix it" response that is encouraged by the dominant medical model (Meyerson 1994, 645). Using this approach, quality of life is of the utmost importance. Dying is not seen as a failure but rather a normal and natural event.

The psychosocial model is not wedded to objectivity in treatment. This model acknowledges that because we are human beings, subjectivity between practitioner and patient is inevitable. In fact, it is encouraged. Rather than

adhering to a scientific, rational approach to patient treatment, these practitioners follow a model based on compassion and empathy for each individual. They recognize their patients' and their own emotions as critical components of the treatment process. Some emotional involvement is seen as normal and acceptable. It may even help patients to achieve the goals they (theoretically) have set for themselves. And while practitioners may burnout on occasion, that too is considered a normal aspect of the social circumstances of their jobs (Meyerson 1994).

Clearly, the ideal-typical medical model and the ideal-typical psychosocial model counter each other at every turn. Attempts to combine the two approaches in practice are bound to create contradictions. Yet Hometowners were forced to attempt this exact combination. I argue that though this benefited management, it also resulted in contradictory messages and expectations for those who worked on the front lines with patients and families.

I am not the first to suggest that the models are contrasts of each other (cf., Goldner 1999; Deierlein 1996) or that theoretically, there are difficulties/tensions in attempting to combine these two models (cf., Searight 1994; Stein 1990; Brown and Zinberg 1982). But I am the first to show some of the difficulties empirically. In this chapter I show, at the level of the actual work of health care practitioners (in this case hospice workers), the tensions that can arise for front-line workers when these models are attempted to be combined in daily practice.

## **The Mixing of the Models and its Consequences for Workers**

In this section, I divide the models into five major components. For each component, I show how Hometown Hospice followed both the dominant medical model and the competing psychosocial model in some way. I also show how their attempt to combine the two incongruous models resulted in contradictions and difficulties for the workers. Those practitioners working face-to-face with the patients and families bore the brunt of Hometown's attempted amalgamation of two disparate models of health care.

### *Specialization of Skill, Practice, and Tools*

In the dominant medical model, health care practitioners have a specialized division of labor. They are trained to do specific tasks with specialized tools of their trade. The psychosocial model entails a less rigid division of labor, with practitioners' tasks overlapping somewhat. Hometown Hospice showed both specialization and overlap in their division of labor. This had consequences for the front-line workers, particularly the nurses.

In informational packets, Hometown Hospice defines its care approach by describing the work of each type of practitioner, one at a time. They say that the registered nurses are in charge of "pain control and symptom management;" nurse's aides do "personal care;" social workers assist with legal matters and provide "counseling" to patients and families; chaplains provide "spiritual support;" volunteers provide "help" for patients and families; and physicians and a pharmacist are there for "consult." This description suggests very little overlap

in what each practitioner does. It suggests a somewhat rigid division of labor and specialization of tasks.

The team meetings mostly corroborated this division. Nurses tended to discuss patients' medical issues, social workers discussed emotional and social factors, and chaplains focused on more spiritual topics. The workers spoke to the physicians and nurses as the medical experts in the room. In the meetings, the practitioners tended to follow the rather rigid descriptions of their jobs given in the Hometown informational materials.

However, according to the practitioners, there was not as complete a specialization of tasks in practice as might appear in the meetings. In interviews, the workers told me about the overlap that often occurred when the team concept was put into action. Nurses were said to do plenty of supportive counseling for patients and families; social workers were said to do some spiritual support; and nurse's aides were complimented with having supportive conversations with patients as well. None of these tasks was included in the description of each of these workers' jobs.

During our interview, I asked a social worker about the division of labor in the teams. This was her response:

The [boundaries] are skewed. And they probably should be skewed because when you take a nurse like Jennifer who is a natural social worker. I mean I know she's a licensed nurse but she has some phenomenal communication skills. And her personality suits this work. And so if she wants to go in there and be warm and fuzzy and get my patients talking, she's not stepping on my turf, she's a damn good nurse. ... So ideally, if our nurses also have strong clinical skills, that just makes everything better. It shouldn't be about turf. It should be about, did we provide for the patients and families. And I

don't care who does it. I mean [a chaplain] has sometimes said to me, "wow that was really good." You know 'cause I'll cover some spiritual thing. ... She knew that I did her job. And Jennifer sometimes does my job. (pp. 28-29)

Another social worker echoed her sentiments:

We trade hats quite frequently. I know the chaplains will laugh and call me Chaplain Julie. It's not unusual for me to pull out a prayer book and start initiating prayers. I'm not a religious person but if that's where the family's at and the chaplain's not there right then and there. If that's what they need, that's what I'll do. (Julie, p. 9)

In both of these excerpts, the social workers discussed the overlap of tasks as a normal aspect of the care approach in the organization. They did not refer to the more official, relatively rigid specialization of tasks of the agency. Instead, they implied that they followed a psychosocial model in practice. They did not show confusion or unease about whether they should be more specialized or whether their tasks should overlap. They agreed that the sharing of the work was good for the patients and families, and the practitioners themselves.

Some of the nurses, however, had a different perspective. If you look at the tasks that overlapped, they were primarily the psychosocial aspects of the work. The medical work was rarely said to be shared by other members of the team. One of the social workers discussed this in her interview. She said that "dispensing medical advice" when she did not "have the medical background...would be illegal." She said that she could not "overstep [her] professional boundaries by practicing medicine." Therefore, the medical aspects of the work, the nurses' jobs, were not conducive to sharing. Nurses took on

aspects of the work beyond their own, but their efforts could rarely be reciprocated by other members of the team.

There were structural aspects of the organization that encouraged the nurses doing more psychosocial labor than others did of their own. Some factors were beyond their control. For instance, the fact that workers needed a legitimate medical credential in order to perform certain tasks, kept social workers and chaplains from being able to change wound dressings, for instance, or to administer medication. Another issue was that nurses were typically touching patients' bodies as part of their work, which encouraged intimacy.

But some of the other factors were simply part of this agency and were, theoretically, changeable. One of the reasons given for why nurses did supportive counseling is that they tended to spend more time with the patients than the psychosocial workers did. Another factor was that all patients had a nurse assigned to them, whereas the social worker and chaplain were optional services. It was not uncommon for a nurse to be the only team member regularly going to see a patient.

One of the nurses connected these factors during our interview:

And so often patients, because the nurses are physically attending to them, they'll confide in you more. There's something about the human touch, and trust and all that. Whereas the social workers have a harder time getting in and really talking. Just being called a social worker is sometimes an obstacle that they have to get across... I think the social workers should be making the two time a week visits and not the nurses so much if there's not physical things. Because the more you're in contact with someone, obviously the more that you learn about them. (Jennifer, pp. 45-46)



This nurse understood that intimate contact encourages conversation between patient and nurse, and that social workers did not have such contact. This was not something that could be changed. But she also pointed to the difficulty that social workers sometimes have just getting in the door to see patients. Though she didn't say so explicitly, the policy that social workers' services were optional further impeded their contact with patients. This in turn led to more work for nurses.

In addition, the practitioners' frequency of visits was a decision on the part of management, and therefore changeable. In the excerpt above, Jennifer expressed her belief that social workers should actually see patients more often than nurses. This would theoretically reduce some of the extra work (beyond pain and physical symptom management) that nurses would do. She had taken her suggestion to management but it had fallen on deaf ears.

During the nurse meeting with the executive director that I observed, several nurses referenced the extra work that fell on nurses. For instance, one nurse said: "I think a lot of what we do is emotional support and counseling." She suggested that social workers assigned to the patient introduce themselves during the admission (the very first visit with the patient) rather than later, when their services were often refused. Her reasoning was that "they spill their guts during the admission," and therefore could feel a closeness with a particular social worker before deciding whether or not they would accept social work services. This nurse didn't want to deal with patients "spill[ing] their guts," because she

saw that as the social workers' job. It fell outside her job description of pain and symptom management. She requested a more rigid division of labor.

The frustration that the nurses expressed can be understood as a response to the fact that the executive director (and the other members of management) neglected to say whether psychosocial work fell outside of, or should be officially included in, the nurses' job description. In effect, they straddled the different models of care. As I showed above, the official description of the nurses' job was "pain and symptom management." The nurses knew they were charged with managing their patients' physical symptoms as best they could. And in the dominant medical model, this alone would be their job. However, the nurses were not explicitly told whether this really was all that was required of them, or whether they should take on much of the psychosocial labor as well. Indeed, if they were encouraged to share these tasks with social workers and chaplains, they would be following more of a psychosocial model.

Given the lack of direction from the members of management, if the nurses followed either model, they were bound to feel unease. If they followed the dominant medical model, they were not sure whether they were fully doing their jobs. Yet if they followed the psychosocial model, where they took on work from the other team members, they felt overworked. By not being told which model to follow, the nurses endured not only confusion, but also a sense of being overworked and under-compensated.

Management benefited by not being explicit. They could not tell the nurses to follow the dominant medical model of rigid specialization, because a

large part of the hospice identity revolves around the “team” concept. Yet, they also could not tell the nurses that they were required to share psychosocial tasks with the other team members, because it was clear that the other members of the team could not reciprocate that work, and management would then have to agree that the nurses deserved more compensation for their efforts. By not telling the nurses what was required of them (i.e., by not being explicit about which model of care the nurses should be following), management squeezed more work out of their employees.

In sum, Hometown followed the dominant medical model by officially defining a specialization of tasks for its employees. However, Hometown’s policies (in conjunction with the intimacy required of nursing work) resulted in nurses feeling charged with their own tasks of pain and symptom management as well as significant psychosocial labor. And though management did not explicitly require this extra work from the nurses, they also did not make efforts to eliminate it from their workloads (or ease their workloads in general). The agency’s attempt to follow both the medical model and psychosocial model at the same time resulted in confusion and frustration, as well as an increased workload, for Hometown nurses. They were left to deal with any unease that they felt in response, on their own.

### *Patient Control*

In the dominant medical model, patients are expected to follow doctors’ orders. They are expected to respect the suggestions of medical experts, and to see expert knowledge as more legitimate than their own. In this model, patient

“noncompliance” should be avoided at all costs. It signifies that the patient is not doing what is best for him/herself. And it makes medical practitioners’ jobs more difficult.

In the psychosocial model, patients ideally play an active role in defining their own conditions and treatment. Health care professionals are supposed to guide patients to help themselves. They use words like “self-determination” and “self-defined” to illustrate how patients should have as much control over their treatment as possible. In the psychosocial model, patients are given options, they are made sure to understand those options, and they choose what they want for themselves. This may make practitioners’ jobs more complicated, but they are confident that patients have self-determination, that they are defining what they want for themselves.

I saw evidence of the dominant medical viewpoint of noncompliance at Hometown, when workers were frustrated with patients and families for not doing what they were told. They frequently spoke as if they knew best, and that the patients or families were acting out of ignorance. I also saw evidence of the psychosocial viewpoint toward patient control of their treatment, when workers discussed (and management suggested) giving patients and families options and letting them choose; and when workers had a neutral, or sometimes positive view of patients and families choosing for themselves, even when it meant going against what the practitioners thought was best. They followed both of the models in their work, even though the two viewpoints are different to the point of contradicting each other. The workers were left to deal with any confusion or

uneasiness they felt about which model they should be following as part of their jobs.

When the nurses complained about noncompliance, the most common reason was medication. Patients (or families) frequently refused to take (or give) certain medications, took less than the amount prescribed, or took them less often than they were prescribed. The typical response to this was that the patient or family needed “teaching”; they did not understand what they were doing. This followed the medical model in that medical practitioners were thought to have a better knowledge about what the patients needed than the patients themselves (or their families) did.

The following is an example of such a discussion:

Nurse: Her pain at best is a 3, at worst it’s a 10. She refuses any more medicine. The doctor tried to give her a Duragesic [morphine] patch, telling her that she does have cancer pain. She won’t touch it.

Physician: Why?

Nurse:....She doesn’t understand that more medicine will give her more function rather than take it away...Ugh. She has no understanding that if you take more, you’ll feel better. She thinks if she puts on that patch, “I’ll die.”

Facilitator/manager names the next patient.  
(Notes 8, pp. 18-19)

In this excerpt, the nurse relayed that the patient said her pain was “at worst...a 10” on a scale of 1 to 10. As a nurse, according to Hometown information materials, her main job was to “manage pain.” This implies that she was supposed to follow the dominant medical model – patients should comply with experts’ orders about how to stop their pain. Yet the patient refused morphine,

the pain medication they most commonly recommended. This patient was then being “noncompliant.”

But the nurse’s job could instead be defined as giving patients options concerning pain control and letting them choose what they would like to do. This would be following the psychosocial model. If she was supposed to relinquish control to her patients, then she had done her job well if she had given this patient options and let her decide what to do.

If this nurse were advised as to which model she should follow, she would know better what actions (if any) to take. If she were expected to follow the dominant medical model, she would know to keep trying to get her patient to comply with her orders. She would also need guidance about the best way to do so, but at least she would have an idea of her ultimate goal. If she were expected to follow the psychosocial model, she would know to continue what she had been doing, because she had succeeded by advising her patient and letting her choose for herself. In this case, she would not be frustrated, because she had done a successful job.

A veteran nurse at Hometown described the psychosocial perspective on this issue during our interview. She referred to a case conference where a social worker was frustrated with a patient and her daughter because they did not have a communicative relationship. She said:

The social worker was getting really just frustrated because she...[felt she needed] as a social worker to “fix it”, their relationship, you know, and [she was] coming to the...realization that she’s not gonna change that. You know and I equated it, I jumped in at that point and said, “you know I equate that as a nurse, that here I want to fix this patient’s

pain, and there are times when the patient doesn't want their pain fixed. You know, they want to have their pain, for whatever reason. And I've got to respect that." You know, as a professional I'm wanting to get rid of this pain, and this patient would rather have a little pain and not be groggy, or whatever their reason is. And it's hard. So yeah, there are lots of problems out there that we cannot fix. But that's not our role. (Connie, pp. 33-34)

In this passage, Connie defined their "role" not as "fix[ing] problems" but instead letting patients choose what they want for themselves. This fits the psychosocial model quite well.

So which was it? Were they there to fix people's problems (which for nurses meant controlling their pain)? Or were they there to give patients options and let them decide for themselves? The practitioners were not given explicit guidance about which model to follow. And since following one model frequently meant not following the other, that led to ambivalence about whether they had done their job well.

There were also things that social workers, charged with supportive counseling, liked for the patients and families to do. Principally, they complimented patients and families who talked openly with them and shared their feelings concerning their lives and their deaths. When patients did not do this, social workers remarked about it, implying or stating that their jobs were made more difficult because of it. Complaining when patients did not want to engage in such conversation meant that they wanted patients to comply with what they thought was best for them. This followed the dominant medical model. If they instead relinquished control to the patients (who may decide that sharing feelings is not going to make them more comfortable), they would be following the

psychosocial model concerning patients' behavior. Again, I saw evidence of both of these viewpoints during my observations.

The following excerpt is illustrative:

Social worker: I went to see [the patient] on her birthday. She's done some life review. She was looking forward to the next visit. Her daughter is just like her. They are guarded and private.

Nurse: [The patient's husband] doesn't have emotions, but he does have chest pain. It was interesting, she said, "I wish they'd talk to me." I said to them, "why don't y'all talk to her?" They all just sit there. ...

Social worker: I've used every tactic I can think of. I've used silence. We all just sit around staring at each other.

Nurse: How about charades? [She giggles]. None of them do emotions. She talks, but she doesn't do emotions either. But just because we think you ought to wail and bang your chest...

Other social worker: That's the way this family has always functioned.

...

Social worker: I'm forcing them to talk about death more. No, I'm just kidding.

Nurse: We're gonna talk about death until you cry! [Giggles.]  
(Notes 4, pp. 19-20)

In this passage, we see the conflict between a social worker getting the patient and family to comply (by talking openly and expressing their feelings before death), and letting the patient and family do what they choose to do. In this case, the patient and family didn't "do emotions." In other words, they did not tend to talk about their feelings with one another. The social worker was frustrated. She said she "used every tactic [she could] think of." She was trying to do her job, but that job could be defined differently depending on which model she was following.



Her comments suggest that she was trying to follow the dominant medical model, which in this case would require that the patient and family comply by opening up to each other.

But the nurse and other social worker attempted to define her job differently. When the nurse said “just because we think you ought to wail and bang your chest,” she was commenting that what Hometowners thought was best might not have been best for this family. And when the other social worker in the room said “this is the way this family has always functioned,” she was validating the family’s lack of communication. With those statements, they were encouraging a view that followed more of a psychosocial model, which lets the cared-for define what they need, rather than the workers.

The point is that this social worker did not receive explicit guidance as to which definition she should follow. She felt frustrated. If she were required to follow the dominant medical model, she could say that she had done her job the best she could, but that the family was being noncompliant. If she were required to follow the psychosocial model, she could say that the family knew their options and were choosing not to communicate about their feelings, and that therefore she had done her job. In either case, it would help to know how what was expected of her. Instead, she was left uneasy, without words to label the source of that uneasiness.

Management benefited from the lack of clarity. The practitioners were not certain which model they should follow, but they also did not think about their work in these terms. The practitioners tended to focus on themselves when such

issues arose in their work rather than explicitly complaining about their patients (which they would do if they were to follow the dominant medical model) or complaining to management. They either expressed frustration with themselves that they had not fully done their jobs or they felt uneasy about the jobs they had accomplished. They were left to deal with these emotions on their own.

When it came to patient control, the practitioners at Hometown Hospice were not told whether to follow the dominant medical model (which requires patient compliance of practitioners' orders) or the psychosocial model (which allows patients to decide from a range of options about what is best for them). If they were supposed to be following the dominant medical model, they would know that they could complain about patient/family noncompliance and ask for guidance about how best to get patients to comply. If they were supposed to follow the psychosocial model, they would have much less frustration because they would know that they had done their jobs if patients chose from a range of options for themselves. Clarity about which model to follow would help them to know how best to do their jobs.

#### *Prioritization of Physical Problems and Physical Solutions*

In the ideal-typical medical model, health care practitioners prioritize individuals' physical problems. Medical experts see diseases as having solely physiological origins. That is, they eschew connections between physical, social and emotional factors. Bodily problems are seen as requiring physical treatment. Medical professionals are trained to see patients as having physical problems which need fixing through their expertise.

The psychosocial model, on the other hand, ideally encourages a holistic approach to caring for patients. Using this model, practitioners see connections among patients' physical, emotional, and spiritual issues. Patients' conditions are often seen as caused by social phenomena, rather than physiological factors. A psychosocial approach to patient treatment encourages a more complicated view of patients' conditions than the one generated by the dominant medical model. Helping people through their struggles is therefore a more complicated endeavor as well.

At Hometown Hospice, I saw evidence of the dominant medical model in this respect, because they prioritized physical problems during the team meetings. Physical problems were mostly treated as though they had physiological causes, and medical solutions. The majority of time during the meetings was spent discussing medical issues. However, they also showed indications of the psychosocial model, in that they discussed some "problems" that were more psychosocial in nature. They also, at times, made connections between patients' psychosocial and physical statuses. However, as you will see, medical solutions were more highly valued than psychosocial ones, favored most likely for their relative simplicity. I argue that the inconsistent uses of both the medical and psychosocial models in this regard had negative effects primarily for the workers focused on patients' psychosocial issues.

In the medical model, practitioners are trained to identify individuals' problems and come up with solutions. Or, as a social worker put it during our interview, "We get sort of wrapped up in diagnosing a problem and providing real

clinical interventions.” That was the model Hometown workers followed when they admitted patients and began working with them. The admissions nurse and social worker identified “problems” for each patient from the list that Hometown used. Those problems then became the practitioners’ focus, at least theoretically.

Each problem tended to be either medical, emotional, or spiritual in nature. In this way, they separated these types of issues in their treatment, with nurses (and nurses’ aides, though they were not part of the meetings) focusing on the physical, social workers on the emotional, and chaplains on the spiritual. The majority of the problems concerned physical attributes, such as “pain,” “breath patterns ineffective,” “nausea/vomiting,” and “constipation.” They used medications (a medical solution) as their “interventions” with these problems. If the problem did not appear to be fixed, they changed the dosage, the frequency, or the type of medication. This took up a great deal of time in the team meetings. In this way, they followed the dominant medical model of treatment.

But they also made connections between patients’ physical and psychosocial issues. One of the veteran employees discussed this during our interview when she said:

There has come to be so much a clear understanding here of the interconnection of what happens to people physically, as well as what’s going on with them psychosocially, spiritually, and that whole mix. And I know that the nurses have become much more attuned to calling the chaplain, calling the social worker, if the person’s in a pain crisis or if they’re having anxiety related problems or sleeping problems. It shows up on our care plans, where our problems are very interdisciplinary as far as the interventions involved. (Eileen, p. 34)

In this passage, Eileen brought up issues that have physical effects, like “pain,” “anxiety,” and “sleeping problems,” and alluded that they might have causes that are more psychosocial in nature. When nurses called the social worker or chaplain about a problem with physical effects, they were paying attention to how the physical and psychosocial were interconnected. Eileen applauded these efforts, and spoke of them proudly. She liked discussing how Hometown fit, at least partly, with a more psychosocial model of patient treatment.

There were times in team meetings where workers seemed to follow both the psychosocial model and the dominant medical model in their discussions of patients. The following excerpt illustrates this:

Nurse: ... We started [the patient] on Prozac but I haven't seen results. She's just as depressed.

Facilitator/manager: How long does it take to kick in?

Other manager/Nurse: Usually 28 days but you can see results sooner.

Social worker: Basically it's a psycho-social situation. The family situation is rotten and getting worse. It's difficult. It's like I lift her out of despair but there's no carryover. It's like having the first visit with a therapist over and over. The daughter is supportive. The son was a long term alcohol and drug abuser and he's now on coke. She's lonely. The volunteer, or a friend will call and she'll say 'no, I don't want to go out.' She's sitting in that house with the curtains closed. She is ambulatory but the patient won't go on errands. ... It's frustrating because she's tormented. I don't know if antidepressants will do it.

Pharmacist: The Prozac should be kicking in. If not, going to 20 milligrams would be appropriate. I would suggest it for next week, if you've not seen any difference.

Social worker: I think this is a long term depression. It's been ten years since her husband died. ... She's not good. (Notes 11, pp. 57-58)

In this passage, the social worker mainly attributed the patient's depression to her family situation. In this way, she was connecting the patient's physical and social issues. She used her expertise as a social worker to describe her perspective on the patient's condition. She was dubious that medication would work for a patient whose major issues were psychosocial (not physical) in nature, and she said so. She followed the psychosocial model of patient treatment in doing so.

However, the medical experts still gravitated toward the simplest response in this situation. In this case, it was anti-depressant medication (a medical response). Notice that the pharmacist still focused on the medication (she recommended a change in the dosage) after the social worker gave her perspective, rather than considering an alternative solution. This was not uncommon. When a patient was anxious because they were going to see a family member they hadn't seen in years or because they felt they were not right with God, there was still the suggestion to give anti-anxiety medication, or increase the dosage. Even when they made the connections between the physical and the psychosocial, medical recommendations were usually favored.

They preferred medical responses not only because many of the practitioners were trained in the dominant medical model. Medical recommendations, particularly medications, were also the simplest ones they could suggest. Solving patients' psychosocial problems was likely a more

complicated endeavor. And the physicians often said so explicitly during the meetings.

The following excerpt from a team meeting is illustrative:

Social worker: He refuses to talk about his terminal status. There's conflict between the wife and daughter about it. He's refusing to discuss advanced care directives. I'll let [the nurse] discuss him.

Nurse: ... He's sinking pretty quickly. As [the social worker] said, he's in denial about his terminal state. Yesterday he made a comment that his pain is under control so now he can concentrate on getting better.

Several people sigh and shake their heads.

...

Facilitator/manager asks if anyone wants to talk about it.

Social worker: The daughter wants to talk about it. The wife was more open on the phone. The pastor has contacted them about funeral plans. So there is some discussion going on, but not with him.

...

Nurse: They put a veil in front of him. They are not going to let him know he is in such bad shape. ... They speak for him.

Physician: These are well-established, years long patterns. There is only so much you can do. He knows how sick he is, he's just not talking about it... (Notes 8, pp. 44-45)

If there were medication for accepting someone's terminal status, I think a medical professional would have suggested it during this discussion. That would have been the simplest response to the problem. However, no such medication exists. That left the focus on the psychosocial. The nurse and social worker agreed that the major issues with this patient were psychosocial ones. They were hoping that they could discuss some possible solutions during the meeting. This did not happen. As I discussed in a previous chapter, the discussions were time-

sensitive. Rarely did the physicians or members of management make real suggestions to help practitioners with specific problems. When the practitioners' pleas for help were acknowledged, others would suggest a "case conference."

Management benefited from the lack of clarity among practitioners about whether they should follow a psychosocial (i.e., holistic) care model or whether they should follow the dominant medical model (i.e., focus on the physical care of patients.) They could not say to do the latter, because the psychosocial folks would be superfluous on the teams. The nurses and nurses' aides would perform the physical tasks necessary, and the work would be done. However, if they said to follow the psychosocial model, they would have to stop giving priority to physical issues, and really acknowledge the importance of the work the psychosocial folks do.

Instead, management had the best of both worlds. They had practitioners who were trying to be all things to all of their patients by prioritizing the physical AND offering more holistic care to patients. They were able to focus on physical issues during team meetings but to expect that their workers offer holistic care to patients anyway. And they were able to call themselves holistic but only give lip service to psychosocial issues during team meetings. They could identify as holistic but not give any real psychosocial guidance to their practitioners.

The physician's concluding statement in the excerpt above is illustrative of this last point. Rather than give guidance to practitioners in regard to difficult and complicated psychosocial issues, on several occasions the physician in the team meetings suggested that the work was futile anyway. In the above excerpt, the



physician said that these family patterns had been going on for “years” and that there was “only so much” the practitioners could do. She suggested that this was perhaps a waste of time, and that they could not possibly achieve their goals.

In sum, Hometown folks followed both the dominant medical model (by prioritizing physical problems and focusing on physical solutions) and the psychosocial model (by making connections between physical and psychosocial issues.) The practitioners were not given guidance about which care model to follow. This meant that the workers felt responsible for all aspects of the patients’ care: medical, psychosocial, and spiritual. They always had issues with patients that needed to be addressed.

And since with either model physical issues would be concentrated on, psychosocial work was given less attention. Indeed, since psychosocial responses to problems were more complicated than medication (the prime medical response), management tried to avoid such discussion. Social workers and chaplains were not encouraged to seek assistance during the meetings, especially because they were under such time constraints. One of the social workers I interviewed agreed, when she said, “If it’s medication related you’ve got your support there, but if it’s something else, you know, you’re supposed to talk about it at another time.” The practitioners worked hard, received little guidance, and were left to feel unappreciated.

#### *Objectivity Versus Subjectivity*

Following the dominant medical model, health care professionals are trained in the scientific vein. They are taught to prize objectivity. They use

scientific tools and technology in order to claim objectivity in their efforts. In the process, medical experts transform patients into puzzles that can only be solved intellectually. Ideally, in this model, experts give all of their patients the same objective and fair treatment.

The psychosocial model, on the other hand, is not wedded to objectivity in treatment. This model acknowledges that because we are human beings, subjectivity between practitioner and patient is inevitable. Treating each patient exactly the same, given the diverse factors in each situation, is impossible. The psychosocial model encourages creativity, in that workers can assist patients with their problems in any number of ways. In this model, treating patients as though they are special is not a sign of favoring them; it is a sign of good work.

At Hometown, the practitioners followed the dominant medical model in their frequent use of objective, quantitative measures to determine how a patient was doing. They especially used such measures to decide whether a patient was sufficiently declining (a topic I discussed in greater detail in a previous chapter). In these determinations, the physicians in particular took whatever pieces of the patient puzzle they had (weight changes, blood counts, scan results) and tried to put them together to form a conclusion. They used specialized language in the process, which further promoted an objective view of the patient (Leif and Fox 1963). As you will see below, the physicians told the nurses to try to treat patients alike, so they did not come to expect special treatment.

However, Hometowners also followed the psychosocial model in that their actions often suggested that subjectivity in treatment was inevitable, and even

good. They did not really treat each patient the same, nor did they sound like they wanted to. They often referred to the “special” things that they did for patients, the “extras,” the “out of the box stuff.” They liked to think of themselves as “different” from hospitals or other health care provider organizations, and the extras that they did were a large part of that identity.

Hometown practitioners followed the dominant medical model when they objectively measured patients’ disease processes in their attempts to determine patients’ prognoses. They treated patients the same when they worked from the same general problem listing for each patient, and used similar medications for somewhat similar symptoms. I discussed this at more length in a previous chapter. Yet they also tried to individualize the treatment they gave to patients. Individualized care was one of the foundational aspects of hospice, after all. And some elements of that carried over into contemporary Hometown caregiving, operationalized by doing “special” things for patients or “out of the box stuff.”

One of the veteran employees at Hometown discussed this in her interview. She had recently decided to move out of front-line care into an outreach position. She invoked the special things hospice workers do as part of her explanation for how she made the decision to shift positions:

...When I wasn’t doing any of that thinking out of the box stuff anymore. When it was enough to go do well what was at hand, and then just close the book and go home. I realized that that’s not quite what hospice is all about. You can get that in a doctor’s office or a hospital setting. But we’re different, and that’s part of what makes hospice just so unique and so personal. And when you’re not doing that, then you need to step back and look at yourself. (Eileen, p. 13)

I asked her to give examples of what she meant by “out of the box stuff” and she told of taking one patient for ice cream on each of their visits, and driving another patient’s sister, who lack transportation, to pay her bills. She was proud of these extra things she had done for patients and families. And she commended other workers who “give that extra piece of themselves.” She was not alone in this view.

One of the ways they provided extras to their patients was through a program established with a local religious community. Hometown workers would request baked goods through this program, and the folks would bake cakes, pies, and other treats for patients and families. Hometown workers provided these baked goods for anniversaries, birthdays, and other special occasions. They referred to the program frequently during the team meetings. They were visibly proud of their efforts, and they complimented the folks who donated the treats.

During a psychosocial staff meeting that I observed, they watched a videotape of the Joint Commission on the Accreditation of Hospitals reviewer’s comments concerning how well Hometown fit their standards. When the reviewer implored the workers to document their efforts more clearly, one of the things she said was: “It should be relevant to patient care, not like he had a chocolate doughnut and I had a glazed doughnut.” During the comment and question session after they watched the video, one of the social workers said: “She says she wants us to tell our story - what does she mean?...I mean reflecting some of the extra-special things we do. Those aren’t getting in. The things that

distinguish us. I know she said ‘don’t tell what kinds of doughnuts.’ But with this [baked goods] thing, or recognizing a birthday or whatever...”

No one ever responded to her comments; someone changed the subject directly afterwards. Nonetheless, her statements reflected aspects of the psychosocial approach to patient care at Hometown. She was proud of the “extra-special things” that Hometown workers did for patients. She wanted “the things that distinguish[ed]” them to get validated in some way. But those things did not fit into the documentation necessitated by the dominant medical model.

Yet again, attempting to combine the two models created contradictions. In this case, it left the social worker feeling confused about which model she should prioritize. Should the workers focus on “relevant” documentation in the way it is defined in the medical model, thereby excluding the extras that made hospice care special? Or should they focus on the individual treatment they gave to patients, providing less time and energy to the required documentation? Doing the former entailed glossing over a piece of the hospice “we’re different” identity, while the latter would result in low ratings from Medicare or Joint Commission reviews. Neither choice was without consequences. And the social worker did not receive any answers. She was left to deal with any unease she felt about the situation, on her own.

Clearly, Hometown workers were proud of the “extras” that they did for patients. But the following excerpt from a team meeting discussion of a patient illustrates the mixed messages practitioners received about this issue:

Nurse manager: ...I think we need to set up some boundaries [with this patient]. We need to stop the idea that nurses aren't as good because they don't do little things.

Nurse: I've been doing range-of-motion with [the patient] and I said, "I can't say other nurses will do that." I don't think I've gone above and beyond. That's part of good care.

Physician: I'd rather you teach her to do it. One of the hardest things I teach people - you have to be as consistent as can be. Once you step out, they see they're getting special treatment. Whether it's a pat on the back, a cake or whatever, they'll start to expect more and more and more. That's because there are no limits set at the beginning. It makes a difference.

...

Social worker: I'd like to say something. You can't fault Jennifer for being an outstanding nurse.

Nurse manager: We're not saying that. (Notes 12, pp. 21-22)

In this excerpt, the physician preached to the nurse that patients all needed to be treated the same. She said, "Whether it's a pat on the back, a cake or whatever, they'll start to expect more and more and more." She discouraged "special treatment" here, following the dominant medical model to a tee. But the nurse argued that she was doing "good nursing." She may have been doing more than what was called for in the dominant medical model, but she did not see that as problematic. Instead, she was proud of her efforts. And the social worker validated her by saying they couldn't "fault [her] for being an outstanding nurse." The nurse received contradictory messages about how to best treat patients. Should she give the best individual care she can give? Or should she treat all patients the same? She was left to deal with any unease she felt as a result.

Management again benefited from the lack of clarity. By having practitioners follow both the psychosocial model (by encouraging subjectivity in treatment) and the dominant medical model (by encouraging objectivity in treatment), they were able to have the best of both worlds. They were able to say that Hometown Hospice offered individualized care, while at the same time pleasing the bureaucratic medical organizations that required proof of objectivity in treatment. The practitioners were required to offer extras to patients and to document as if they were treating all patients the same. This created some contradictions for them, but they were left to deal with that on their own.

#### *Maintenance of Professional Distance from Patients*

The dominant medical model requires emotional distance from patients. Emotional involvement with individual patients is proscribed. According to this model, emotional involvement impedes objectivity, therefore hindering practitioners' abilities to do their jobs (Haas and Shaffir 1977). Concern for patients as individuals may lead to preferential treatment of patients and burnout on the part of the practitioner. For these reasons, it is discouraged.

Those following a psychosocial model, on the other hand, are encouraged to have compassion and empathy for each individual. They recognize their patients' and their own emotions as critical components of the treatment process. Some emotional involvement is seen as normal and acceptable. It may even help patients to achieve the goals they (theoretically) have set for themselves. Occasional burnout is considered a normal aspect of the social circumstances of their jobs (Meyerson 1994).

Hometowners showed evidence of the dominant medical model in this respect. One of the social workers spoke about the importance of keeping a professional distance from patients and families, during our interview. I asked her if she ever kept in touch with families after patients died. She said that it was not “professional” to do so. She expanded that by saying that in general, “if you’re being friends with people, you aren’t doing good therapy. You’re not setting those boundaries.” A nurses’ aide referenced this as well when she said: “You have to keep a professional distance. That doesn’t mean you’re cold.” These sound like what is expected in the dominant medical model, in which emotional involvement is proscribed. If you are not maintaining a professional distance, then you are not doing a good job.

Hometown practitioners also showed “affective neutrality” (Parsons 1951) in the team meetings, thereby following the dominant medical model. They never cried, even when discussing particularly sad issues. But they frequently said “it’s sad” when discussing patients’ physical or psychosocial circumstances. They used the passive voice to reference a “sad” situation. This allowed them to show a generalized compassion for their patients, but not to sound emotionally involved in their lives. As Schwalbe (2002) argues, “[it’s sad] uses the language of feeling but implies detachment” (p. 191). The frequent use of this phrase showed the influence of the dominant medical model on their conversations.

The practitioners also showed affective neutrality in their initial responses to the dramatic events on September 11<sup>th</sup>, 2001. These events occurred before and during a Blue Team meeting on that day. The two planes had already been



flown into the World Trade Center buildings when the meeting began. We received only a few periodic updates during the meeting from people who had left the room and come back again. At one point, a nurse came in and said, “The Pentagon’s been hit.” Several people looked alarmed for an instant. Then the physician in the meeting said, “Well, what do you want to do here folks? There’s nothing we can do, I think we should try to keep going.” And the facilitator/manager (a social worker by training) agreed, saying: “Just try to stay focused.” They continued with their discussion of the particular patients’ issues. They maintained an even emotional keel and finished the meeting as if it were any other day.

However, Hometown workers did not show complete emotional detachment in their work. After all, empathy and compassion were sold as part of the Hometown package of patient care. Therefore, they were encouraged to care about their patients and treat them empathically. Though they did not cry in the team meetings, several workers told me about crying in front of patients and families. And on the rare occasion that they mentioned such crying during the team meetings, they were not discouraged from doing so.

The following excerpt from a team meeting discussion is illustrative of the existence of the psychosocial model in their work:

Social worker: [The patient] lives in a small camper, with no way to heat up food. He cannot take a full bath. The volunteer is wonderful, helping him with social isolation and with meals. I called his nephew and said he needs some way to cook his own meals. He needs to get gas put on. ... I’m just so touched by the whole visit last week, with the [baked goods.] It’s the only time I’ve ever teared up in front of a patient, in ten years as a social worker. The impact it made on

him was just... I took him food from the [baked goods program] and the card for Valentine's Day because he doesn't have anybody. He first said, "Heaven must've sent you and hospice." When I brought the cookies, he just cried. It was more than I could bear.

Nurse: It was okay to cry.

Social worker: He said, "I'm an 84 year old man. For some people who don't even know me to care enough to make cookies and this card. Please express appreciation for me."  
(Notes 3, 23-24)

In this excerpt, the social worker referenced some of the extras of which Hometowners are so proud. She also mentioned her own expression of emotions in front of a patient. If Hometown were solely following the dominant medical model, this admission would be proscribed. Her statement about this, and the nurse's validation that it was "okay to cry," were evidence of the psychosocial model in their work.

Though the workers rarely referenced crying in front of their patients and families at the team meetings, they did not hide such expression of emotion from me during interviews. One social worker said, "You can't help but feel their pain... I mean I cry with my families, you can't help it. You know, you're not human if you don't." Another social worker echoed that when she said, "I think we're only human and if we fight back the tears when we really want to cry, that's doing everybody, yourself, the family, the patient, a great injustice." In these statements, the workers followed the psychosocial model, which says that showing emotion is a normal, natural aspect of good caregiving.

A veteran showed evidence of the psychosocial model on their work when she said the following during our interview:

Eileen: When [there's a] potential for a very helpful intimacy, [then] when there is crisis or stress, you're not making an introduction, you're not cutting new ground, you're ready to step right in, at a safe place with people. I think that's a lot of it, Molly, is finding that safe place for people.

Molly: And "safe place" means?

Eileen: Where they can share whatever they need to at whatever depth. That they know that it's gonna stay where it needs to. That they know they're still gonna be respected and honored, regardless of how they let their emotional underwear show. (p. 12)

She advocated a psychosocial perspective here, saying that emotional involvement or "intimacy" between practitioner and patient can actually be a positive thing. She stated that patients and families should feel comfortable sharing their feelings with Hometown workers. And emotional intimacy between workers and patients and families can help that along. Emotional involvement does not have to be a hindrance (as is assumed in the medical model); it can actually be of assistance.

Interestingly, Hometown Hospice also showed evidence of the psychosocial model in their response to the events of September 11<sup>th</sup>, 2001, *after* the team meeting ended. Directly after the meeting, everyone present at the office at the time was called into the conference room. The bereavement counselor lit a pottery candle with a cloth wick and placed it centrally in the room. The executive director thanked her. He said a few words and then passed the platform to one of the chaplains, who said a short non-denominational prayer. She spoke of "people without peace in their hearts," and finished with "of faith, hope, and love, the greatest of these is love." Several people gave updates on the situation,

for the benefit of those who had been in the meeting. During this, more than a few of the workers cried openly. Some were consoled with hugs. The performance of this ritual and the open expression of emotions showed that this organization did not explicitly follow the dominant medical model and its strict expectation of emotional detachment.

The practitioners were not given guidance as to which model they should be following in this regard. If they were working in a more conventional medical model, at least they would know what was expected of them: detachment. They would know to never show emotions in front of patients or families, to never share themselves with them or become involved with their lives. Whether they followed that or not, they would know what was expected of them. If they were working in an explicit psychosocial model, they would know that showing emotions would be seen as more normal than not. They would know that the expression of emotions could be helpful in their jobs, and not always a hindrance. Again, they may not always follow the expectations, but they would know what they were.

Management benefited from the lack of clarity in this regard. They expected practitioners to follow both the dominant medical model and the psychosocial model in ways that benefited the agency. For instance, the practitioners did not explicitly show emotional involvement in the meetings, and therefore the members of management could avoid uncomfortable emotional displays and the effort needed to address them. And by not proscribing emotional involvement with patients, management could expect practitioners to offer the

compassionate care that they marketed as part of the Hometown care package. They had the best of both worlds: they were able to promote Hometown as consisting of “loving, caring and sensitive professionals,” while at the same time discussing issues with practitioners in a relatively unemotional way.

With both care models in juxtaposition, Hometown workers had to constantly negotiate the correct amount of professional distance and emotional involvement they showed. They did not want to appear cold as that would go against the hospice philosophy. But they did not want to appear emotionally overwhelmed either, because burning out was associated with not being able to handle the work. As Weigert and Franks (1989) argue, expecting both “empathic, personal concern and rational, universal detachment pose[s] acute tensions for medical and helping professionals” (210). Hometown practitioners were asked to follow two contradictory sets of expectations, and left to deal with any unease they felt about their work, on their own.

### **Existing Research on Health Care Models**

Before I draw any conclusions, it is necessary to review what the few past researchers have written about similar issues. I show that though several scholars have discussed similar ideas, only one has really discussed the actual attempt of disparate health care models in practice, and the difficulties/tensions that result. I also acknowledge that in essence, Hometown’s hands are tied when it comes to the combination of models, but that management could still make things easier for the front-line workers.

Several scholars have called for a change in the biomedical model, though they have different emphases in their exhortations. For example, Lorber (1997) calls for a “socio-biomedical” model of health care. She wants medical practitioners to consider social causes when diagnosing illness, and social solutions when prescribing medical care. She argues that the prioritization of the physical in practice means the disregarding of social issues. She thinks that social phenomena are at least as important if not more important than physiological matters, and that health care practitioners need to give more attention to them.

Engel (1977; 1980) calls for a “biopsychosocial” conceptual model of health study and care. He thinks that physicians in particular should have knowledge at all levels of life: molecular, physiological, psychological, microsocial and macrosocial. In order to understand what is going on at any of the levels, physicians need to understand all of them. He emphasizes that his model is a scientific one, as opposed to the biomedical, holistic, and humanistic models, which all have come to constitute dogmas.

Both Lorber’s model and Engel’s conception are idealistic. Neither would be completely feasible in practice, as they expect medical practitioners and in particular physicians to carry the lion’s share of the burden of patient care. Their models are different from what was being attempted at Hometown in that Hometown spread out its burden of care to a number of different health care practitioners. No one person was expected to have all of the knowledge or do all of the tasks involved. Hometown’s attempted model was also different in that it focused on the physical and the psychosocial. It did not expect practitioners to

have a broad, sociological perspective of patients as is expected in both Lorber's and Engel's theoretical models.

Goldner's (2000) idea of "integrative medicine" comes closest in the literature to describing what Hometown attempted. She refers to the integration of "Western medical techniques" with "alternative medical techniques and ideology" (215). And Schneirov and Geczik (2002) conduct a case study of a "complementary" (alternative) medical clinic which existed as part of a prominent American hospital, and show some problems that resulted (which I discuss in greater detail in Chapter 6).

But these models, though analogous, are not the same. Though the version of Western medicine is virtually identical to what I call the dominant medical model, their description of "alternative" medicine actually differs from the psychosocial model being attempted at Hometown. For example, the goals of alternative medicine are health and well-being whereas the goal in hospice is comfort for the dying. Also, in what is called the "alternative" medical model, drugs are avoided, whereas hospice fully embraces the use of drugs for managing pain. In general, Hometown Hospice practitioners did not describe their care as "alternative medicine." Practices such as herbal remedies, chiropractic techniques, biofeedback and acupuncture were simply not discussed as part of Hometown's plan of care. Though they did offer massage therapy on some occasions, they did not refer to this as "alternative medicine."

This study is therefore the first to empirically show the tensions that can arise when health care practitioners attempt to combine a biomedical model with a

particular kind of model that differs from the conventional: the *psychosocial* model, in practice. When front-line workers are not clear as to what model they are expected to follow, they do not know how to define the goals of their work and therefore cannot see when they have successfully done their jobs. Confusion and frustration can result. But these are not inevitable.

I acknowledge that Hometown Hospice did have a dilemma. They could not be fully psychosocial, because they were an accredited health care provider with Medicare certification, so they had bureaucratic requirements placed on them from prominent medical organizations. And they could not follow a pure biomedical model, because then nothing would set them apart from any provider of care to the dying. Being different was a major part of their marketing strategy. In that sense they were forced to attempt to combine the models.

However, members of management could have given front-line workers in the team meetings more guidance as to what model to follow when (as well as more assistance as to how to go about following each model). The workers could have been shown that there were different ways to define their jobs, and therefore different goals to accomplish in different situations. If they were made clearer on this, a lot of unnecessary feelings (including frustration from thinking they have not done their jobs, anger that they are under-compensated for their work, and unease from hearing contradictory messages) could have been avoided.

### **Conclusion**

The “medical model” is the dominant model of health care that medical practitioners follow. Its ideal-typical components include: a rigid specialization



of tasks, compliant patients, the prioritization of physical problems, objective patient treatment, and emotional detachment from patients. There is at least one competing model available for those who practice health care. The components of the ideal-typical “psychosocial model” directly contrast those of the medical model at each point. In the psychosocial model, the sharing of tasks is preferred over specialization, patients should have as much control over their treatment as possible, the physical is interconnected with psychosocial issues, the inevitability of subjectivity in treatment is acknowledged, and emotional involvement with patients is not discouraged and may be welcomed.

I argue in this chapter that at Hometown Hospice, they were forced to attempt to combine these two contradictory models in practice. The front-line workers were given conflicting messages about which of the above components to follow, and which to dismiss. This lack of clarity benefited management in various ways. But without clear expectations, the workers themselves often felt unsure if they had fully accomplished the goals of their jobs. They were left to deal with any unease they felt as a result. The practitioners who worked face-to-face with the patients and families ultimately bore the brunt of Hometown’s attempted amalgamation of two different models of health care provision.

In the next chapter, I further discuss the challenges involved in the work of Hometown practitioners. I show how bureaucratic requirements, as well as the necessity of negotiating the actions of such varied people as patients’ families, primary physicians, and the staff at residential facilities, brought about unpleasant emotions for the workers. I argue that they dealt with these by using humor in

their discussions during the team meetings. By complaining through joking, they were able to maintain identities of sympathetic professionals.

## **Chapter 4**

### **Complaining Through Joking:**

#### **Hometown Workers' Challenges, and**

#### **Managing the Unpleasant Emotions That Resulted**

In the previous chapters, I show some of the facets of the work at Hometown Hospice that caused the front-line employees difficulty. In this chapter, I discuss these more fully, focusing on an interactional strategy they used to deal with them: humor. Prior to attending the team meetings, I expected their discussions to be serious in tone. These practitioners were working with the terminally ill, after all, and I equated dying with seriousness. I was therefore struck by how much joking there was during the discussions. I began keeping track of every time they used humor in their interaction with each other, and I soon had pages and pages of fieldnote excerpts to analyze.

In this chapter, I show that those front-line practitioners who were present at the team meetings had certain challenges to overcome in the process of providing comfort and support to the terminally ill and their families. These challenges resulted in numerous emotions for the workers, including frustration, aggravation, and powerlessness. Humor with each other provided some relief from such unpleasant emotions. During the team meetings, they complained about the causes of various unpleasant emotions through joking. In the process they showed each other that as long as they were lighthearted about it, they could complain and display unpleasant emotions and still maintain identities of

sympathetic professionals. Since their meetings took place in what Goffman (1959) called a “backstage” area, away from patients and families, the workers could use humor that might not seem congruent with the wholly sympathetic image that they had to project in more front-stage areas (i.e., those in the presence of non-hospice employees.)

In the process, humor bonded them together. Using humor, they conveyed a sense of understanding with each other. They also sent the message that these serious things can and should be used in humor. They legitimated the use of humor and they made accounts for it. They communicated to each other, and myself, that even though dying and laughter may not go together outside of hospice, within hospice they must, to be able to do their jobs.

Previous research on medical providers has also found that they use humor to manage emotions (cf., Smith and Kleinman 1989; Meerabeau and Page 1998). This analysis contributes to that literature by focusing on the management of unpleasant emotions that result from the somewhat unique challenges of hospice workers. The challenges I discuss in this chapter come from attempting to follow the bureaucratic regulations that the dominant medical model requires, while simultaneously attempting to enact a holistic philosophy.

### **Challenges, Unpleasant Emotions, and the Necessity of Humor**

The work of Hometown practitioners involved numerous challenges, all of which were apparent in the team meetings, interviews, and other discussions I observed, or engaged in with them. As I made clear in previous chapters, they were forced to work within the constraints set by their own bureaucratic

environment, including the requirements of documentation and various Medicare regulations. They were also forced to work with patients and families with varying levels of understanding of hospice and other medical issues, different personalities, and different degrees of willingness to be helped. They were forced to deal with physicians who had varying degrees of understanding about hospice. They were forced to deal with managers who gave them conflicting guidance, discouraged creativity, and offered little support. Many practitioners also had to work with the staff at residential facilities, who frequently had little understanding of hospice, and whom they saw as less competent caregivers. And they were all faced with death, and the grieving of others, on a regular basis.

These challenges led to numerous emotions, including frustration, aggravation, and powerlessness, as you will see below. In the following paragraphs, I look at each of these challenges, and show how the practitioners complained about the challenges through humor. This provided some relief from their unpleasant emotions and bonded them together in the process.

#### *Bureaucratic Requirements*

As I stated in earlier chapters, the rationalization of Hometown Hospice involved various bureaucratic elements that became a part of their work. Hometown practitioners frequently indicated frustration with bureaucratic requirements, as I have shown previously. One of the ways in which they managed this frustration in the team meetings was to complain about their bureaucratic system through joking. In particular, they mocked the documentation requirements and the specific rules and regulations that were

apparent in their work. In order to portray a humorous perspective about these elements, a certain knowledge about the Hometown bureaucracy was necessary. Francis (1994) calls humor “an expert cultural performance” (p. 149) and Hometown Hospice bureaucratic humor was no different.

### Documentation

Hometown Hospice workers joked about many aspects of their bureaucratic system. The most common attempts at this type of humor had to do with documentation. They recognized the centrality of written communication in their work, and commented on it through humor. For example, they regularly mocked the “problem listing” that they use to categorize each patient. As discussed in previous chapters, these include “nurse problems” like cardiac output decreased, nausea/vomiting, thought processes altered, and weakness/fatigue, as well as “psychosocial problems” such as coping difficulty family, and grief. The workers knew that they had to address these problems in the meetings, and write something about them on the team sheets. As a way to deal with the frustration of this constant and tedious task, they joked in their discussions about the problems, and in reference to what they would write about them. They also achieved other interactional goals through this humor.

Let me give a few examples. In the following excerpt, a social worker introduced a patient using the standard format, with a little twist:

Social worker: 70 year old patient of Dr. -----. Ecog 3.5. Problems are breath patterns ineffective, cardiac output decreased, coping difficulty family, home maintenance management impaired, and nurse going out of her mind.

Several people giggle.

Nurse: That's right. He is very much in decline. He has heart failure and kidney failure. He is so much weaker. So I don't think he'll drive the family much crazier. ... He refused a hospital bed. He's just lucid enough to say "No." I don't think he'll last 14 days.

(Notes 5, p. 12)

The social worker played with the routinized script here, by adding a problem of "nurse going out of her mind." In so doing, she introduced this patient, who had been very difficult from their perspective, in a humorous manner. She showed her support for her coworker, sending a message not only to the frustrated nurse but also to the others in the room, that this patient had been so difficult that he deserved commentary. By defining the situation as at least somewhat humorous, she precluded the possibility that the nurse would approach the discussion too seriously. If the nurse were to show her true frustration with this patient in the meeting, she may show too much emotion, therefore making others in the room uncomfortable. The social worker set it up so that this did not happen. In this way, she managed the emotional tenor of the discussion even before it began.

Another example of humor using the problem listing began with the nurse with a particular patient's team meeting sheet, saying to the social worker, "coping difficulty family?" This is a shorthand way of asking what is happening under that category. The ideal typical response would be a succinct summary of how the family is coping, something that can be written on the team meeting sheet that shows the problem is being addressed. Instead, the social worker rolled her eyes, shook her head and said "Yes, very much so." Several people giggled. She poked fun at the problem listing in this response. She knew that she was

supposed to attempt to “close” (essentially resolve) the problems listed for each patient/family. In this case, using humor, she noted the impossibility of that task. By saying “very much so,” she remarked that she was overwhelmed by the complications involved.

She also knew the efficiency requirement during team meetings. Again, in this case, she was saying that the complications defied efficiency. The quickest way for her to say what was happening was that the family was having plenty of difficulty coping. She got some laughter in response, which showed others’ support. She then went on to say, “It keeps going on and on,” and spoke for a few sentences in defense of her somewhat glib comment. Therefore, she did not appear as if she was giving too much levity to the situation. As with virtually all the humor attempts I observed, this was a short one. She segued immediately to a more serious discussion of the problem.

The following excerpt of Hometown Hospice workers using the problem listing in an attempt at humor, is from a meeting of the Residential Facility team. These folks met to discuss patients in the skilled nursing and assisted-living facilities with which Hometown had contracts. This is taken from the middle of a discussion of a patient:

Chaplain brings up the “sitting room” in the facility where the patient lives.

Social worker: There’s nothing in there. They are just sitting there like this. (She slumps over onto the table and has a spaced out expression on her face.) It’s a crime. Because they’re paying good money to be in that unit.

Nurse/ facilitator: So under “grief,” I should write “social worker grieves.”



Nurse: And nurse. “Hospice team grieves appropriately.”  
(Notes 16, p. 38)

In this exchange, the social worker was clearly upset about the treatment of the Alzheimer’s patients in this particular facility. Indeed, this was not the first time that she had complained about the lack of care and attention the patients in this “sitting room” received. The others in the meeting agreed with her, but instead of responding in a similarly serious tone, they changed the tone to one of humor. The nurse/facilitator put a humorous spin on the documentation requirement in her statement about what she could write under the patient’s problem of “grief.” By saying that the *social worker* “grieves,” she simultaneously recognized and downplayed the social worker’s frustration. She essentially said to her, “I know you are upset, and that the situation is upsetting, but do not let it get to you. You need to take things a little more lightly.” She therefore changed the emotional tenor of the discussion, using a Hometown bureaucratic requirement (something they could all understandably joke about) to do so.

Another nurse took her comment a step further, showing her agreement with both the social worker’s frustration *and* the facilitator’s assessment. When she said that the “nurse and social worker grieve appropriately,” she also poked fun at a routine social work phrase. Social workers frequently wrote in the documentary reality that a patient or family member were “grieving appropriately,” to show that the person did not need assistance in that area.

## Medicare Regulations

The problem listing was not the only ritual into which Hometown Hospice workers injected humor. They also used Medicare regulations in their humor, to manage their frustration with them. Most commonly, they used the Medicare requirement of discharging patients who did not appear to have six months or less to live, in their attempts at humor. For example, the following fieldnote excerpt is derived from a discussion about a patient who appeared to be doing well, but was over 90 years old and had several potential problems:

Physician: There are enough things to monitor, so people cannot take issue with us keeping him on.

Nurse/facilitator walks in the room after being gone a few minutes, and social worker asks her opinion about the patient's hospice appropriateness.

Nurse/facilitator: Oh, he's very appropriate. Oh, God forbid. He's the last person in the world I'd want to d.c.[discharge].

Social worker: I said that, but I wanted your expertise as an RN.

Nurse/facilitator: He had chest pain, but it might be gas.

Physician: I think it's angio [heart related].

Social worker: I agree with the doctor. (She smiles.)

Nurse: That's what we want...

They giggle. (Notes 5, p. 37)

The fact that this attempt at humor may not seem so funny to people outside of hospice corroborates Francis' (1994) claim above, that humor is an expert cultural performance. In order for a person to consider this exchange as humorous, s/he has to understand hospice Medicare regulations. Their joking about this patient's

medical problems was not an attempt to say that they wanted this man to be sicker than he was. Instead, their goal was to keep him in their care. And they knew that, frustrating as it might have been, they needed a physician to say that he was declining enough to justify keeping him (and spending Medicare monies on him). This can be seen as an example of “gallows humor” to which observers of medical providers have referred (Smith and Kleinman 1989; Yoels and Clair 1995). Taken out of context, this may seem like an unprofessional and inappropriate comment. But within an environment where only hospice practitioners are interacting, there was a shared understanding of the consequences for this patient (possible loss of hospice care). They could therefore joke about his apparent decline.

In virtually all cases when they joked about discharging a patient, they wanted to keep the patient in their care. In the following excerpt, the physician was concerned about a patient’s hospice appropriateness. In regard to this, the patient’s nurse joked to another nurse:

Physician: Can we get [the primary physician’s] notes from last year? We have to say if he’s six months. We need to see if his weight’s decreased or something. A COPD [Chronic Obstructive Pulmonary Disease] person who’s not on 24 hour oxygen, that’s a big red flag. It’s hard to argue in the absence of something else. I understand it’s problematic but that’s the way it is.

...

Nurse to other nurse (and, by default, to myself): I don’t want to discharge him. What should I say? We could throw him on the floor and say he fell. Oh, that’s awful.

She giggles.  
(Notes 22, p. 43-44)

This nurse's comment is a good example of one that could only be made "backstage." Indeed, she did not even make the statement to the whole group at the meeting, but only to the nurse sitting next to her. (I was within hearing distance, so she acknowledged me with her eyes as well.) In this excerpt, we again see a Hometown worker who did not want to discharge a patient. Based on other comments she had made, this was purportedly because she liked him and wanted to continue to be his nurse. Therefore, her comment about throwing him on the floor was not supposed to be taken seriously. She knew that if he fell, that could be enough to justify his Medicare recertification. So what may appear to be an inappropriate comment became allowed when it was conveyed in this particular social context, with a humorous tone.

Another Medicare regulation that they joked about was the reimbursement of patient's medications. With regard to medication, Medicare monies paid to Hometown could be used only for Medicare patients' medications that were related to their primary hospice diagnoses. Therefore, Hometowners had to be careful how they diagnosed such patients when they were admitted, and choosy with what medications they "covered," or paid for with Medicare monies. And they had frequent debates during team meetings about whether certain "meds should be covered" or not. Sometimes, they tried to make complex connections between a diagnosis and a medication, so as to help Medicare patients financially (by having Medicare pay for the medication rather than the patient him/herself). The relatively high frequency of these discussions shows that it was an important issue at Hometown. And practitioners got frustrated in these conversations.

Those most concerned with the patients' financial welfare tended to want the pharmacist and billing staff to be liberal, whereas those most concerned with the possibility of an audit wanted to err on the conservative side. Whatever the case, this issue lent itself well to some humorous comments.

I have several places in my notes where they discussed a patient who drank alcohol either on occasion or frequently, and someone commented about whether the alcohol was "covered" or not. For example:

Nurse: The man, my God, has a good sense of humor. He has episodes of shortness of breath. But he follows commands. I'll say "Is there anything I can get you?" He'll say, "A shot of bourbon."

People giggle.

Facilitator/manager: Will we cover it?

Pharmacist: Only if we all get it. I used to have hospital patients have a toddy at night. That was fine with me.  
(Notes 7, p. 53)

In this short excerpt, there were several humor attempts. First, the nurse shared her patient's statement about wanting a drink, and she got some laughs. She supported the patient's statement by saying he had "a good sense of humor." She was grateful that even with a terminal illness, he had the capacity to joke. It may very well be a serious issue if he chose to drink alcohol, but the nurse here at the meeting set this up with a humorous definition of the situation. The facilitator then followed her lead and joked about Medicare regulations concerning reimbursement for medications by saying that alcohol could be "cover"ed. Finally, the pharmacist herself joined in, showing her support for the patient and for the levity of the discussion, saying "only if we all get it." The potential

seriousness of a terminally ill patient doing more damage to his body with alcohol, and the frustration of having to make sure that all covered medications were relevant to patients' primary diagnoses, were defused through these humor attempts. Through this quick exchange, the participants achieved several interactional goals.

In another example of a Hometown practitioner using Medicare reimbursement of medications in an attempt at humor, we see the facilitator trying to make a humorous connection between two disparate items: a diagnosis of congestive heart failure, and medication for back pain:

Nurse: ...For pain he has a Duragesic [morphine] patch and he takes extra strength Tylenol. Sometimes his back still hurts him. But that's what he fractured, so. Sometimes his feet bother him, with stinging. ... We're not even paying for his pain meds because of the fracture of the sacro.

Facilitator/manager: Couldn't we say it's due to his heart failure? That it's due to an oxygen deficiency in the brain, because of his cardiac status?

She and others giggle.  
(Notes 8, pp. 33-34)

In this exchange, the facilitator tried to do what the practitioners were frequently attempting, that is to make a logical and hopefully legal and fair connection between a patient's primary diagnosis and the medications s/he was taking. They did so to make themselves safe from auditing problems, and to help the patient financially. In this case, however, the facilitator did so in an attempt at humor. She knew that there was no (legitimate) way to justify Medicare paying for pain medication for a fractured back when the patient's diagnosis was heart failure. The symptom (back pain) was completely unrelated to the diagnosis. She made

this statement to bring levity to the situation in general, and, more specifically, to manage the frustration of always having to follow Medicare regulations. If not for this rule, Hometown workers would be freer to choose the criteria by which they covered medications. Again, other interactants needed to understand the context in which this was stated, in order for anyone to find it humorous.

### *Family as the Unit of Care*

As I have discussed in previous chapters, one aspect of the hospice philosophy is that the patient's family is seen as "the unit of care." This means that the plans of care for each patient involve not only the patient him/herself, but also the patient's caregivers and other involved family members. One social worker in our interview said she described this to the primary caregiver of a new patient as follows: "He's the person with the disease, but the family is the unit of care. And we want to provide support and care to everybody who's being impacted by this, and especially you."

Families, then, constitute another layer of support and care provision at Hometown. Some of the "problems" in Hometown's plans of care that indicated this were the commonly used "knowledge deficit" and "coping difficulty family." The practitioners worked with patients and families with varying levels of understanding of hospice and other medical issues. Those with a dearth of such understanding were given the problem "knowledge deficit." This meant that the family members involved needed some "teaching" on these issues.

They used the problem of "coping difficulty family" to indicate family members who were not dealing with the dying of their relative in what would be

considered a healthful manner. This was typically used if any of the family members was not realistic about the impending death of the patient, or if the family was extremely anxious about what was happening (or what could happen) with the patient. In the following excerpt from a team meeting discussion, we see a social worker addressing the “coping difficulty” of a patient’s daughter:

“Coping difficulty family. I’m still working with the daughter, but also with the paid caregiver. We’ve talked about death and dying and coordinated discussion between her and the daughter about what to do when he dies and how to address it. The daughter now feels free enough to not be there when I go to the house, which is a big step for her. She just kind of freaked out again when he had trouble breathing.”  
(Notes 3, p. 43)

As you can see, they tried to recognize and gradually address different family members’ coping difficulty. This was a continual process. I never observed, for example, them “closing” the problem of coping difficulty. This would have indicated that the family members were all coping fine and that they could be expected to continue to cope healthfully, without further assistance to that end.

Hometown practitioners attempted to help the families understand, and cope with, what was happening on a regular basis. And they had to do so with family members with different personalities. In fact, as one of the chaplains said in her interview, “[We have all] gotten fired from a team. And it was just because something didn’t match personality wise.” She went on to describe how different practitioners’ “styles” did not always suit the personalities of the patients/families to whom they were matched. The family members were not always welcoming of the “teaching” or other assistance that Hometowners offered.



Hometown practitioners frequently displayed their frustration with family members during the team meetings. However, with only one exception (that I discuss below), they did so in a humorous way. They complained about families through joking. In the process they showed each other that as long as they were lighthearted about it, they could complain and display unpleasant emotions while still maintaining identities of sympathetic professionals.

The following excerpt from a team meeting discussion is illustrative:

Nurse: ...[The patient] is an angry person. You can cut the hostility with a knife in the air. They're just a delightful couple.

Other nurse: Tongue in cheek.

...

Social worker: (sarcastically) They have a loving, adoring relationship. (She shakes her head.) They have no children.

Other social worker: Thank God.

Social worker: As each of them talks, the other one's eyes are rolling. ... I kept the two of them together. With so much going on, I know she'd not be happy with me talking with him alone. He complains about the work he has to do to help her. She doesn't know the pain he's in.

...

Nurse: How often will you subject yourself to this?

Social worker: Once every six months.

People giggle.

Social worker: Four times the first month, three times thereafter. ...  
(Notes 4, pp. 39-41)

In this excerpt, we get a taste for how they discussed a difficult family. In this case, the social worker in particular felt frustrated with the circumstances under which she had to work. She showed that this was a complicated and difficult

family situation. The nurse showed her support when she asked “how often” the social worker would “subject [her]self to this.” The social worker managed her frustration and lightened the serious emotionality of the conversation when she said “once every six months.”

Her attempt at humor was successful for a number of reasons. For one, they all knew that every six months was much too infrequent for them to see patients. This was knowledge that came easily when doing this job. Another is that they all had had difficult patients/families, whom they would have liked to visit this infrequently. Therefore, they showed camaraderie and empathy with the social worker. At the same time, their laughter expressed relief that they did not have to deal with this family. Again in this case, we see the situation defined only briefly as humorous. After a few giggles, the social worker responded to the nurse’s query in a serious manner. She had achieved brief levity and support from her colleagues; the interactional goals for her use of humor had been met.

A frequent challenge for the workers was that families expected more from Hometown Hospice than what they offered. This, along with patients/families not understanding medical issues, constituted “knowledge deficit.” Families had to be reminded of the kinds of services that they offered, particularly that they did not offer round-the-clock, in-house care. (Although on-call services were always available). When families did not agree with the policies, or were unwilling to be taught about medical issues, this caused frustration for the workers.

In the following excerpt, we see just such a situation discussed.

Nurse: The wife manipulates the meds. She'll implement whatever and then wonder what happened. She's now driven out two home health aides.

Home health aide supervisor: Three, and a volunteer.

Nurse asks why the last home health aide won't go anymore.

Home health aide supervisor: He'd call and say he'd be there by 10 and she'd say he can only come at 2. Well if you have patients in [one area of the county], you do all of your patients there before you go to the next area.

Nurse: That's not just aides. People expect that of nurses as well.

Facilitator/manager: Does she realize it's because of her demands?

Social worker: She feels she has the right to make those demands. Hospice is not going to provide the care that she needs.

Nurse: It's not 24 hour care.

...

Doctor: How's the patient?

Nurse: With the morphine, that sedated him. She lowered it. ... She'll call me all the time, call [his primary physician] on her personal beeper number, call on-call.

Doctor: It's normal to be sedated for two, three, or four days.

Nurse: She won't hear it.

Doctor (shaking his head): Poor man.

Doctor suggests they be "very nice to her, very understanding," and see what she does.

Nurse: She does crocodile tears. She's exhausting.

Doctor says she needs a "Prozac drip."

Nurse and others giggle.

Facilitator/manager names the next patient.  
(Notes 32, pp. 39-40)

In this excerpt we see some of the expectations that families had of Hometown workers. The wife of this particular patient wanted more of the practitioners' attention than they offered. She wanted to dictate when the workers came to the house, and was inflexible in her "demands." She also was resistant to the nurse's medical lessons, including that it was normal for morphine to sedate a patient for a particular period of time. Instead of waiting, this patient's wife changed the medication herself. For the nurse, who wanted to provide physical comfort to the patient, this family member presented a challenge. She was frustrated.

After she and the others expressed their frustration, the doctor offered some guidance and then jokingly suggested that the wife needed a "Prozac drip" herself. This would not have sounded funny if it were stated about a patient, because they did prescribe Prozac drips for patients when they thought it appropriate. But they all knew that even if they wanted to, they could not prescribe a medication for a patient's family member. This was a situation where suggesting a medical response to a problem was actually humorous, because the family as "the unit of care" did not include medical care, only emotional and spiritual care.

In this situation, the hands-on practitioners themselves were not the ones to make the joke. However, the doctor who did make it offered support to those who were frustrated with this woman, with his statement. He also suggested to those in the room that this was an appropriate thing to joke about, and others

followed suit by giggling. Though the situation was not resolved, the conversation at least ended on a lighter note than how it began.

### *Working With Primary Physicians*

In order for patients to be admitted to Hometown Hospice, they had to be referred by their primary physicians. Each patient had to have a primary physician the entire time they were receiving Hometown services. Therefore, Hometown nurses had two sets of physicians they worked with on a regular basis: Hometown physicians and patients' primary physicians. Hometown physicians acted only as consultants to the nurses. It was the patients' primary physicians who prescribed medications, signed Medicare forms, and had to approve any changes in their patients' care. Hometown nurses had to get and follow orders from primary physicians.

Some physicians were considered more familiar with the hospice philosophy of care than others. In Chapter 1, I say that the practitioners preferred to work with physicians who were "savvy" about hospice. This meant that they were knowledgeable about hospice appropriateness – that patients had to be seen as having six months or fewer to live, and that they were forgoing the use of curative treatment in favor of palliative care and symptom management. To the extent that doctors were not hospice savvy, the nurses got frustrated.

They dealt with their frustration in the meetings by injecting humor into their complaints about primary physicians. The following excerpt from my fieldnotes, taken from a team meeting discussion of a patient with terminal cirrhosis, is illustrative:

Nurse: Mr. L----- went to see Dr. H----- on Monday and Dr. H---- was really, really pleased with the changes in Mr. L---- and how well he's doing. He said he needed daily exercise, and that his wife could do this. His wife is a tiny, frail thing. And he said "well, if the wife can't, then the sons can." I talked with the doctor and those were his exact words. He also said, "The patient is doin' much better. He has months or years to live." He doesn't think he is end-stage. I said, "I am sure [the hospice physician] would be happy to give you a call." I didn't know what to do. I thought I was goin' to kill him.

Giggles.

Doctor (sarcastically): Thanks.  
(Notes 28, p. 34)

This nurse had expressed frustration with this particular physician in past meetings. But this time, she showed that she was frustrated enough to suggest that he talk to one of the Hometown consulting physicians. This was a rare occurrence, and something that the nurses tried to avoid. She expressed frustration particularly with his statements that the patient was "doing much better," and that he has "months or years to live." Later in the discussion, she repeated that he said "months or years." She was incredulous that a physician of a hospice patient would simultaneously think this, and think that he was hospice-appropriate.

When this slight, good-natured nurse shook her head and said "I thought I was goin' to kill him," everyone laughed in response. The Hometown physician went along with the joke and sarcastically thanked her for passing the buck to him. The nurse complained through joking, which helped her maintain the identity of a sympathetic professional. And the doctor, and the others who laughed, showed their support and understanding in their response.

### *Residential Facility Staff*

Several Hometown practitioners had to negotiate not only working with patients' families and primary physicians, but also with the staff (and the conditions) at various residential facilities. They managed the frustration, aggravation, and powerlessness that resulted from these challenges by using humor at their expense. This occurred most often at Residential Facility team meetings, where Hometown practitioners discussed patients at skilled nursing and assisted living facilities.

Some context may be necessary. The great majority (over 80%) of Hometown patients lived and died at home. Therefore, Hometown staff were primarily trained to work with patients and families in a home setting. However, Hometown did get referrals for patients who lived in facilities. (Approximately one-fifth of their census at any given time lived in facilities). And, according to a veteran nurse who had done a lot of work as a liaison between Hometown and residential facilities, what is required of hospice practitioners differs in the two settings:

Working with facilities is a completely different, it's not like going into homes where you're just dealing with the patient and the family. When you go into facilities, you're working with the patient, sometimes the family, and then you're working with this layer of staff, and that can be very complicated and time-consuming, and there's a lot of teaching, and there's a lot of PR, and there's a lot of "let's not step on anybody's toes," but let's also get, be the patient advocate. (Connie, pp. 15-16)

She emphasized the *staff* at residential facilities as the important piece that was missing when Hometown practitioners worked with home patients. She called the

relationship between Hometowners and facility staff “complicated and time-consuming,” and alluded to the tension that can exist between the two.

Hometowners were frequently frustrated with the facility staff’s lack of understanding of hospice care. They therefore referred to “teaching” the staff in many different ways. When I asked this hospice nurse what it was that facility staff had to be taught, she said, “You know, about the hospice philosophy, and pain control, and hospice management of care and that whole thing.”

The relationship between the two staffs was potentially conflictual. This was particularly evidenced by statements made by one of the managers during an early one-on-one meeting. I asked her about Hometown nurses going into facilities, and she said that in facilities, “traditionally, the goal is for patients to get better.” Hospice, on the other hand, emphasizes palliative rather than curative care. She said that facility “staff are resistant to give pain medications. They use respirators, and force feed patients.” Again, these do not align with hospice’s ideal mission. She went on to say that some staff are “resentful of other nurses coming in and telling them what to do,” and that some employees at facilities “bristle with the intrusion” of Hometown workers there.

Clearly, there was plenty of potential for tension between Hometown workers visiting patients in facilities, and the facility staff themselves. One of the ways in which members of the Residential Facility team managed the frustration that accompanied this tension was to criticize facilities in general and staff in particular, in their attempts at humor during team meetings. When they used such humor they also implied that hospice care was better than care in these settings,



and therefore praised themselves while they condemned facilities. In this way, their use of humor was congruent with a descendant of Freud's theory of aggression, which claims that people use humor to compliment themselves at the expense of others (Berlyne 1968; La Fave et al. 1976; Francis 1994).

In the following example, we see Hometown workers implying their superiority to the care in a residential facility:

Nurse: [The patient]'s been bed-bound for months... He went to [the facility]. It was the first night they were open. He fell.

Gasps and sighs from others.

Nurse continues: They put his urinal in the bathroom.

Physician (sarcastically): Well, that's really good.

Nurse: He'll have a heck of a strain for that!

She and several others giggle.

Nurse continues: She was upset. There were only 3 patients and 2 staff members. It's a new facility...  
(Notes 2, pp. 25-26)

In this excerpt, we see an example of a Hometown patient who had fallen, while under their care. This man was elderly, very ill, and, as the nurse says, had been bed-bound for a significant period of time. A fall could have been very dangerous for him. The interactants acknowledged that, gasping in response to the news. When the nurse gave further information to help them understand (that they put his urinal in the bathroom), humor became possible. The physician set the stage by shifting the focus from the fall to the facility's culpability. The nurse then commented that "he'll have a heck of a strain" as a result. She and the others laughed in relief. They achieved superiority in the exchange, through the

implication that they would never have put a bed-bound patient's urinal so far away from the bed. And their concern, and possible guilt, about the patient's fall was managed by the joke. This was all accomplished with a quick shift in the definition of the situation from seriousness to humorousness, and back again.

In another brief humorous exchange during a Residential Facility team meeting, a nurse used a bureaucratic imperative to take a crack at the staff at a particular facility. The following occurred as the social worker who had the team meeting sheet for a particular patient, was going through the list of the nursing "problems," asking what should be written for each:

Social worker: Knowledge deficit.

Facilitator/ nurse: The staff don't know how to take care of her.

Laughter.

Nurse: [Write] "continue to instruct staff about disease process."  
(Notes 10, p. 30)

In her snide comment, the facilitator clearly criticized the staff at the facility where this patient resides. She knew that what she said was not acceptable for their documentary reality, so even though she may have been actually critical of the staff, this was meant to be taken as a humorous comment. Others found it funny for two main reasons. For one, they knew that "staff don't know how to take care of her" could not be written on the team meeting sheets. The more common response to "knowledge deficit" was that the staff were receiving some sort of teaching about hospice.

The other reason the humorous attempt was successful was that it gave the workers a chance to break from the many serious emotions they felt in their work with patients in facilities. The subcultural context is very important here. These were not just Hometown workers here, after all, these were Hometown workers who worked in residential facilities. They had a shared understanding of what these settings were like, and shared frustration as a result. They may have exaggerated how difficult their work was. Regardless, this attempt at humor allowed them all to claim their superiority over facility staff, to mock their bureaucratic system which so values formal, written communication, and to manage their serious emotions, if ever so briefly.

The following excerpt contains another telling exchange, including several humorous and sarcastic comments aimed at non-hospice others:

Nurse: I have a question about managing [the patient's] "breath patterns ineffective." They [at the facility] said that according to the rules they can't give her morphine, or they don't want to give her morphine. And also that according to OSHA, there can be no egg crates, and that the state won't allow them to have full side rails. I need suggestions. She was on Ativan in the hospital.

Physician: Why no egg crates?

Nurse: They said they are a fire hazard. I said only if you light it!

Several people giggle.

Nurse (sarcastically): She's fallen six times since Sunday. That's not an issue. If they caught on fire, that would be a problem. (She shakes her head).

Physician: Does she have dementia? That's probably a good idea not to have side rails.

Nurse: I think she had a stroke in the last week. ... She has horrible breath sounds. She's on 2 liters of oxygen all the time. Knowledge deficit - that's a continuous problem with the staff. I'm figuring out what all these rules are. The director is adamant about it.

Pharmacist: Is this assisted living?

Nurse: Assisted living.

Social worker (sarcastically): I'm sure looking forward to going there now.

Nurse: When did OSHA start getting involved in patient care? I thought they were for workers.

Social worker: If the bed's on fire, there is more to worry about than egg crates!  
(Notes 7, pp. 24-25)

In this excerpt, we see a nurse who was looking for help with a multi-faceted problem concerning a patient at a particular assisted-living facility. Again we see some real frustration on a Hometown practitioner's behalf. This time, she was frustrated with bureaucratic rules and regulations outside of hospice that she thought were constraining her ability to care for this patient. But the humorous and sarcastic comments that she and the social worker made were actually aimed at the residential facility itself. The comments about fire potential may not seem humorous outside of this cultural and situational context. But in a setting with these particular interactants, they were not only humorous, they also heightened hospice care in comparison to the alternatives.

In this final exchange from a Residential Facility team meeting, we see a serious conversation defused with what a veteran Hometowneer in her interview called "hospice humor":

Nurse: No one [at the facility] understands what we ask. The son, he and I put her back to bed. I changed her. She has a d.u. [bed sore] on her butt. ...They can't understand.

Social worker: And there's no one there.

Nurse: It's a frightening place, with such potential for abuse.

Social worker: And neglect.

Nurse: They sit them in chairs, and leave them.

Chaplain: That's what happened yesterday.

Pharmacist: This lady has nothing for pain. She has got to be uncomfortable.

Nurse: If we sedate her, they're not goin' to feed her.

Pharmacist suggests ibuprofen liquid.

Nurse: I think she could tolerate that. She eats all the food they give her if they stay long enough.

Pharmacist: She's got to be uncomfortable.

...

Social worker: It was interesting because I spent time with the daughter. To see pictures of Mrs. J----. She was like an Aunt Bea mom, the neighborhood mom, who baked cookies.

Nurse: And she laughed all the time.

Social worker: Just a joyful woman.

Nurse: It's hard to see them treat patients like that.

Pharmacist: 10 ccs instead of 20... also chewable tablets.

Nurse: Chewable tablets are better. I think they'll give her the right amount. She'll chew.

Pharmacist: See if that'll ease up a little bit.

...

Chaplain: While I was waiting for her to get in the room, I saw them dragging others around.

Nurse: Either they're not trained or they don't give a flying flip.

Social worker: Even the patient who died that day. They wanted her up in a chair.

Nurse: Just 'cuz you're dead does not excuse you.

Facilitator/ nurse laughs loudly while others giggle.

Pharmacist asks where this is.

Nurse: [Treasure Hollow]. It was [Southern Bend]. A family owned it, then a corporation. Then [one of their residents] got hit by a car and they changed their name.

Several people shake their heads, huff, and chuckle.  
(Notes 22, pp. 34-36)

The facility discussed here was criticized in a serious manner throughout this exchange. The nurse, social worker, and chaplain who visited this facility each had grave concerns about its treatment of patients. This kind of conversation was relatively common in the Residential Facility team meetings, and this one really showed the Hometown practitioners' emotions. They were particularly dismayed at the neglect they felt the patients were enduring.

I remember listening to conversations like these and wondering if someone in the room would lighten the mood. Even I, as a non-participant observer, felt very serious and low during such exchanges. And looking around the room, the gestures of the interactants matched their words – they would shake their heads, look down, sigh. They often sounded as though they felt powerless, and sometimes angry, at the treatment some patients received. So, when the nurse criticized the facility's practice of getting everyone up in their chairs, saying “Just

cuz you're dead does not excuse you," several of us took that as a chance to feel momentary relief from the frustration induced by the feelings of powerlessness.

The nurse's humor attempt was clearly an emotion management strategy. It exemplifies each of the components of humor that Francis, in her enlightening 1994 article, identifies. She defines humor as "an expert cultural performance which strengthens or restores the feeling norms of the situation and creates amusement in the self and others, generating positive sentiment among members of an interacting group, ...often at the expense of some excluded person(s)." (p. 148). I have already shown how Hometown humor depends on shared cultural understanding. In this example, the interactants understood the feelings that accompany visiting patients in facilities that they consider sub-par. The nurse's comment did re-establish "feeling norms" in that the conversation had become serious enough to bring down people's moods. She generated amusement and therefore positive emotional displays among the team members. And indeed, the humor was directed at an excluded party. Yet again we see humor used in a denouncement of staff at residential facilities.

#### *An Exception*

There was one (and only one) discussion where a practitioner complained about a patient's family and did not agree to a humorous definition of the situation. A nurse was upset that a patient's wife had altered his medications significantly. Her tone implied frustration and powerlessness about the situation. When the pharmacist suggested that the patient might not need the cardiac

medications his wife had stopped, the nurse said, “But he will need them. He has a big floppy heart.” She sighed.

To lighten the tone of the discussion, the manager/facilitator said, “A big floppy heart. Write that down.” One of the chaplains responded, “Is that a technical term?” They and others laughed, but the nurse did not crack a smile. Instead, she said, “It’s called cardiomyopathy.” Others appeared put off by the nurse’s response. She maintained her frustration and seriousness despite an attempt at lightheartedness.

This was important because it was so unusual. It was as if they all agreed that any aspects about caring for the terminally ill that caused unpleasant emotions could, and indeed should, be joked about. Otherwise, a person appeared as not a good sport, or worse, overwhelmed with their work. This particular nurse quit just before I finished observing at the organization. The social work manager said that she was “moving on.” When I said to the nurse manager that the nurse appeared stressed a lot, she agreed that she acted “overwhelmed” and she said she was “not surprised” that she had quit.

#### *Accounts for, and Legitimation of, Humor*

It was as if they realized, though, that joking about caring for the dying may not seem appropriate. Therefore, they made accounts for it, to me. Early on in my observations, for example, one of the physicians said to me, “So many of these situations are so sad. This stuff is so serious. If we didn’t make light of it sometimes. Well, it helps us get through it.” And during a team meeting early in my observations, after a nurse made a humorous statement about a patient’s



diagnosis, a chaplain leaned over to me and said, “Sometimes we have to take things a little lightly.” Also, another veteran worker said, after a humorous statement about an AIDS patient during her interview, “You’ve gotta have your hospice humor.”

They also apologized for their humor to me during the meetings. Several times, after a humorous statement had been made, someone turned to me and said, “Don’t write that down,” and then laughed. Once, after a nurse said that a patient had told her she would be dead before her next visit, and yet she was still alive, the social worker asked, “Did you call her on it?” The nurse responded sarcastically, “Hello. I thought your bed would be empty.” And someone else piped in, “I didn’t expect to see you today.” In an attempt at impression management with me, the nurse manager said, “What are you writing down there? ‘Bizarre staff?’” And the nurse said, “We’re loose today.”

Interestingly, they also legitimated their use of humor to each other, by bringing in a “professional humorist.” The office staff publicized the event by posting flyers around the office over a month in advance. The humorist spoke in the large conference room on a September morning, and the event was so well-attended by the time I arrived that I had to stand in the hallway to listen. When I got there, the pharmacist greeted me and said, “Oh, you should listen to this. He’s really funny.”

He repeated this message time and time again: “Share the laughter.” He used his life experiences to tell humorous stories, particularly about his family, and about the disabled children for whom he had cared. He also told secondhand

medical stories, about patients' experiences in hospitals, with humorous spins. And he put up overhead transparencies of humorous quotes from children, and humorous epitaphs. He had good comedic timing, and the Hometowners in the audience laughed heartily with him. He said, "We need to find laughter and use it for ourselves and our clients. Give them reasons to celebrate."

He ended his talk by saying that he had four main points:

One, death is not funny but what happens around it can be celebrated. Two, the best weapons we have are faith, hope, and love. Three, it is good to have inside jokes – we have to do that for ourselves. Four, some people never see the death and laughter connection, and that's okay. ... Most people don't want survivors to be morose after they die. ... You can laugh and cry at loss; both are appropriate. If you can cry at weddings, laughing at funerals is appropriate. (Notes 30, p. 4)

Their uses of humor, and their accounts for it, were all ways in which they were telling myself and each other that joking about hospice work is good, but within their social context. Humor is an acceptable, indeed encouraged way to deal with the causes of unpleasant emotions on the job. Humor seemed to be a requirement for being a good Hometown worker.

### **Conclusion**

Humor can achieve significant goals in social interaction. In this chapter, I have argued that Hometown Hospice workers used humor as a strategy in their team meetings. Most importantly, they managed their own and others' emotions through humor. In their meetings, Hometown practitioners managed their frustration, aggravation and powerlessness at least partly through humor. They took advantage of their shared cultural understandings by joking about things that

people outside of hospice may not find very funny. And when the humor was successful, the workers bonded as a result.

I have argued that Hometowners used humor to complain about the challenges that arise in the attempt to follow bureaucratic requirements while also enacting a holistic philosophy of care. In other words, they joked about the numerous causes of their unpleasant emotions. And in the process, they changed the emotional tenor of their conversations just long enough to gain a break from the seriousness of their jobs. Humor was a common element in Hometown practitioners' discussions, and a seemingly required emotion management strategy as well.

The challenges discussed in this and previous chapters focus on the members of the professional front-line staff at Hometown. However, the caregiving "teams" included the more marginalized nurses' aides as well. Though I have taken the concept of the team approach at face value to this point, in the next chapter, I unpack the team approach to caregiving that was used at Hometown.

## **Chapter 5**

### **Inclusive Rhetoric and the Maintenance of Exclusivity:**

#### **Hometown's Team Approach to Caregiving and the Inequality it Disguises**

The concept of “team” caregiving was significant to Hometown workers. It was important not only in practice, but also rhetorically. They used the word “team” in their promotional materials to mean all of the front-line caregivers available to patients. They were proud of this “team approach” as it was called, and its inclusiveness. They emphasized that it made their care provision different from the care offered in other settings, such as home health agencies or hospitals. However, there were contradictions apparent in regard to the team approach of the organization. For example, though the team rhetoric was inclusive, the home health aides were excluded from Hometown's team meetings.

In this chapter, I discuss the contradictions in regard to Hometown's “team approach.” I then analyze one attempt at managing the contradictions: the provision of a home health aide appreciation lunch. I discuss how the staff at Hometown benefited from having an inclusive team approach, as well as how it benefited the professional front-line workers to exclude the aides from the team meetings. I conclude with some possible reasons for why the aides themselves may not have pushed for more reality to the rhetoric.

#### **The Rhetorical Usefulness of the Team Approach**

Hometowners were proud of their team approach. They used the language of “teams” in their promotional materials, and with me. In particular, they

emphasized that such an approach set them apart from other health care providers, in efforts to sell their care. In this way, (the rhetoric of) the team approach benefited the agency. In this section, I discuss the usefulness of the team approach for Hometown.

*The Team Approach as Different and Superior*

Hometowners were proud of how hospice care was “different” from other care providing organizations, such as home health agencies and hospitals. The team approach was a pivotal piece of this “we’re different” identity. For example, during an interview with a Hometown social worker, she said the following:

The interdisciplinary team is just really, really important. Because you can go out and I’m not saying anything against nursing but you can apply a band-aid and walk away, but what about that spiritual crisis and that emotional crisis and how to say good-bye and anger at God and all of those things that still make up each and every one of us. ... I think that’s really something that is just so important. Otherwise we’d just be another home health agency. Not that that’s bad. But that’s not what we’re for. (Julie, p. 21)

In this excerpt, she showed that the team approach was a pivotal piece of how Hometown differed from other “home health agenc[ies].” She showed her inclination for the team approach and her pride in how it set Hometown apart from other health care provision agencies.

Similarly, during an interview with a veteran full-time home health aide, I asked her if anything surprised her about hospice work. She said,

I thought it was just like any other agency, which I found out that it’s not. Because like even with the team that we have, you know, other agencies don’t have it. Like we have chaplains and we have social workers going out, nurses, and home health aides. It’s totally different from other agencies. Much better. (Kecia, pp. 36-37)

Though I did not ask her about the team approach specifically, she brought up this aspect of hospice work on her own. Despite her exclusion from much of the goings-on of the teams (as I discuss in detail in this chapter), this excerpt shows her fondness for the approach, and her pride that it distinguished Hometown from other care providers.

In addition, one of the Hometown physicians boasted that hospice is better when she said, “It’s the only place, medically...where there really is a team approach to patients. All the elements get discussed.” This is one of several excerpts showing that Hometowners used “team approach” rhetoric to demonstrate the superiority of hospice.

#### *Team Membership as Inclusive*

Hometowners were not only proud of their team approach for its apparent superiority to other styles of care provision. They also emphasized the inclusivity of its team membership. On their website and in other promotional materials, Hometown Hospice described their team approach in an inclusive fashion. The typical description was as follows: “Care teams consisting of an experienced Registered Nurse, a medical social worker, a home health aide, a chaplain and volunteers are available to every patient.” In this description of teams, they include each paid front-line worker as well as volunteers.

In their elucidation of the team approach to me, Hometowners emphasized its inclusiveness. For example, one of my first observational occurrences was a social worker staff meeting. After explaining my interests and the intent of my research, one of the social workers asked if I was interested in studying one

particular “discipline.” I said that part of what attracted me to hospice was their “interdisciplinary approach” to care. I said that I did not see any reason to study “either social workers or nurses,” and that I would like to study both. In quick response, several people said, “and chaplains,” while others said, “and home health aides,” “and volunteers.” Everyone nodded. Inclusiveness was the party line.

In addition, when I asked one of the nurses about her “thoughts” on “the team approach,” she responded:

It very much helps. If you’ve got a good social worker. If they can form a rapport. Sometimes that’s tough. . . I keep trying to pull in the team. The chaplain is usually great. Home health aides are wonderful. (Tammy, pp. 23-24)

In this excerpt, the nurse mentioned each paid member of the Hometown teams when asked more generally about the team approach at the agency. This shows a focus on inclusiveness.

An excerpt from an interview with a Hometown social worker also illustrates their emphasis on inclusiveness in the teams. She said,

In hospice work we can’t just look at their psycho-social issues or just at their physical pain, or just at their caregiving needs or just at their spirituality. It takes everybody. So there’s this real team approach here. And in hospice if you do it right, the team approach is pure. It’s never . . . any more glaringly apparent how important it is to work as a team, as it is in hospice work. (Shannon, pp. 3-4)

In this piece, she mentioned the work of social workers, nurses, home health aides, and chaplains, in that order, as constituting the “team approach.” She said that “it takes everybody” (i.e., all four types of people), to do hospice work. In

this excerpt, she showed her fondness for the team approach in general, and her view that “everybody” was a necessary and important part of the team.

### **Contradictions in Their Use of the “Team Approach”**

#### *Exclusion of Aides from “Team Meetings”*

The above data show that Hometown Hospice had a team approach to care of which they were proud, as it ostensibly set them apart from other agencies. They clearly believed in this approach, and they emphasized its inclusiveness. However, the definition of team that they used for public relations differed from how they used the word “team” on a regular basis, in the goings-on of the agency. The “team meetings” I observed were attended by only some of the “team” members: nurses, social workers, and chaplains. Volunteers and home health aides did not attend the meetings, so their voices were not heard. Volunteers were unpaid caregivers and therefore were not employed by the agency per se. Home health aides, however, were employees of the organization. And though they were said to be part of the team, they were not included in the team meetings.

Of the thirteen nurses, eleven social workers, and three chaplains I met and observed, all of them were white women save one chaplain (a white man), and one black female nurse. They were all college-educated, and the social workers had master’s degrees. Hometown’s pharmacist was a white woman. All of the physicians were white – two men and one woman. Of the ten home health aides employed in the agency, two were white, and the rest were women (and one man) of color.



In practice, then, nurses, social workers and chaplains, who were white and college-educated, were verified as the actual “teams” by being present at the team meetings. The aides, most of whom were racial-ethnic minorities, were included in the rhetoric of “teams” but were excluded from the teams’ discussion of patients. Despite their inclusive rhetoric, Hometowners perpetuated inequalities in the teams by excluding the aides from the meetings in the first place.

### *Other Contradictions*

This was not the only contradiction apparent in the rhetoric of “team.” The term “team” implies that at a minimum, members of a team know the team of which they are a part. This was not the case for the home health aides at Hometown. An aide illustrated this when she said to me, “I don’t even know what team I’m on.” When I said, “You don’t?,” she asked where the “line was drawn” between the teams. When I told her that Blue Team covered the southern part of the county and Red Team covered the north, she said that she had patients in both areas of the county. A veteran aide corroborated this during our interview when she said, “With the home health aides . . . , most of us do both Blue and Red Team, because of the territory. I cover [areas in both the southern and northern part of the county] . . . It depends on where my patients are.” The aides had varying degrees of knowledge about the geographic boundaries associated with the different teams, but none of them identified as being a member of one specific team.

The term “team” suggests that at a minimum, members of the team talk to each other more than sporadically. However, home health aides did not have office space in the agency, nor did they come to team meetings. They came to the office only to turn in paperwork or to pick up supplies. The aides agreed that the only team members they really communicated with were the nurses, and even with them, as one aide said, “We hardly ever see each other, you know. Unless sometimes we might be in the same home at the same time, but that’s not too often.” Another aide suggested that nurse turnover contributed to this when she said, “There are a lot of new nurses. If I come in contact with them, I might meet them. But there’s no formal gathering to meet everybody. I know the old nurses because they’ve been around. The new ones I might see at a patient’s house.” Without “formal gathering[s]” or inclusive team meetings, aides may not know some of their “team” members, and did not see or communicate with other people in the teams much at all.

One of the main ways in which the professional front-line staff communicated with each other was through Nextel two-way phones that were provided by the agency. As these workers were often on the road or seeing patients, they suggested that this was the best way to be contacted by other team members. However, the agency did not provide these phones to home health aides. One of the aides in our interview said that the aides “asked for [them] and they won’t give them to us.” This exclusion further delineated who were treated as full team members, and impeded the possibility of communication between

aides and the other people on the teams.

*An Ironic Account for the Contradiction*

How did Hometowners account for the contradiction between the rhetorical inclusiveness of teams and the reality of exclusion? When I asked the social work manager about the home health aides' absence from the meetings, she said, "Unfortunately, they cannot be part of the team meetings. They are too busy. They may have 6 or 7 patients to see a day." Other members of management corroborated this reasoning. Based on my observations and interviews, it was indeed the case that aides were with more patients per day, and with each patient more often, than the other front-line workers. This suggests that aides' knowledge of patients was more complete than the other practitioners. Yet instead of making their presence at the meetings more imperative, these factors were used as reasons why they could *not* attend the meetings.

One of the social workers made a similar connection during our interview. When I asked her how much she talked to the aides, she said,

Kara: Sometimes I'll leave the aides a message if I think there's something that [they should know]. And I don't know how much the nurses interact with the aides. But you know I think we're all a team. And unfortunately the aides are the ones that see the patients and get the most interaction, talk the most to the patients, and sometimes we leave them out of the loop. Or we don't even know who they are. I mean I never, you know, I just happen to run into them sometimes in the home.

Molly: And they don't go to the meetings.

Kara: But they're a critical part of the team. Probably as much as anyone on that team. (Kara, pp. 11-12)

This social worker recognized that the aides may have had the most to offer in a conversation about patients. Yet she admitted that the aides were not always even known by the other team members, much less kept in “the loop.” Though the aides were a “critical part of the team,” they were not treated as full team members.

### **Managing the Contradiction Between Rhetoric and Reality:**

#### **Home Health Aide Appreciation Week**

There was evidence that Hometowners recognized that their team rhetoric did not match the reality. In an effort to balance the lopsided value given to the different front-line positions in the agency, for example, they declared a week in November “Home Health Aide Appreciation Week.” They did not have such an occasion for any other position in the agency. The enactment of this appreciation week was a “surprise” buffet lunch on that Thursday. Nurses provided the food, and all of the employees of the agency were encouraged to attend. In the subsequent pages, I describe the most relevant pieces of this lunch in regard to my argument in this chapter. I then discuss their sociological relevance in the paragraphs that follow.

The lunch took place in the conference room where the team meetings were held. There were buffet tables set up with different food offerings, and each of the meeting tables was covered with a red and white checkered tablecloth to eat upon. I was one of the first to arrive. As people from various positions in the agency began milling into the room and chatting with each other, the home health aide supervisor announced to the aides, “Well, folks, I told you this was a

mandatory meeting but really this is an appreciation lunch for you. We just wanted to say ‘Thanks’ for all that you do, and that’s from the nurses and social workers and everyone else here. So, here’s your lunch.” A few people applauded, but many chatted through this announcement.

After the announcement, a few people began to line up to get their lunches. However, several of the nurses and social workers pushed the aides to line up first for food. They said things like, “Come on, it’s your day.” They encouraged the aides to stand and line up. One social worker looked as if she was pushing people out of line so that the aides could line up first. The aides generally smiled shyly, and slowly made their way to the buffet tables.

The buffet line got very long, and people proceeded to get their food. After doing so, people tended to sit with those with similar positions in the agency. The office staff sat together, the aides sat together, and the nurses and social workers sat together. One nurse, two social workers and a chaplain sat amongst the aides while they ate, but after eating they left their seats to talk with others.

At one point, the nurse seated amongst the aides greeted the aide next to her and she responded, but called the nurse by an incorrect name. When she realized her mistake, she apologized shyly. The nurse said, “Don’t worry about it. I get you all mixed up all the time.” She smiled as she told a story about how she had recently approached an aide and said, “Are you one of our new girls?” The aide had responded that she had been working there for over a decade. The nurse giggled and said that she just had not met her before.

While people ate, the home health aide supervisor asked for everyone's attention and suggested that all in attendance say their names and what position they held in the agency. The office staff started, and they went around the room. When the first home health aide said her name and her position, people clapped for her. Some applauded for each of the aides as each introduced herself.

After the introductions, as people continued to eat, the same nurse who sat amongst the aides stood up and said that she would like to say something. She said,

I wanted to say that we know, ... just how kind and compassionate you all are. You clean folks up and you talk with them. We couldn't do it without you. And we recognize, even though you might not see it, we see how kind and compassionate you are and I just want to say that we couldn't do it without you and we really appreciate it. (Notes 35, p. 6)

Several people nodded as she sat down. A few people clapped.

Then, a veteran worker in the agency stood up and said that she had been at Hometown "from the beginning," and so she had to "say a few words." She proceeded to say the following,

What you all do is just so important. What the nurses do, that's important, but what you do that's just really important. And we see that and we very much value the information that you have. We know that you communicate a lot with the nurses and so the information that you give us through the nurses is just really invaluable. It's unfortunate that you cannot come to the meetings. It's unfortunate that we just haven't been able to work that out logistically. But the information you give through the nurses is really important. And what you do is really appreciated. And you all know these patients better than anyone. And when I go into the homes and I have this name tag on that says "Pharmacist," that is often intimidating to people. But you go in there and people talk with you and feel comfortable with you. And we really could not do all of this without you. (Notes 35, p. 6-7)

After she spoke and sat down, people nodded and then continued to talk amongst themselves. I turned to one of the aides and said, “So this was a surprise, huh?” She said, “Yeah. I guess it’s home health week. I didn’t know anything about that.” She shrugged.

Then, the home health aide supervisor came around the room with a stack of hardcover books. She showily gave each aide a copy of the book *Dying Well*, saying to each, “a gift for you.” On each book was a sticker saying “Compliments of [Hometown Hospice].”

Though some aides stayed for awhile longer, most left soon after the gift was given. They all said that they had more patients to see, so they were anxious to leave. As the last aides left the room, one of them, the only male aide, shook my hand and thanked me for having this lunch for them. Before I could explain who I was, he turned back to his coworker, and they walked out of the room.

After everyone had left, I helped the home health aide supervisor clean up. I asked her, “Is the turnover high for home health aides?” She shook her head vigorously, looked at me quizzically but sternly, and said, “No. No.” She said, “I try to take good care of them.”

#### *Analysis of the Appreciation Week*

The fact that the agency even declared a week Home Health Aide Appreciation Week showed that Hometowners recognized that aides were not given sufficient indications of appreciation. It would be redundant to have an appreciation week for people who were already shown acknowledgment in other ways. Though they called it an appreciation *week*, the actual representation of

appreciation was a lunch and a book. During the lunch, the aides were showered with brief attention, as they were pushed to eat first, applauded when they spoke, and given words of praise. This was an effort by the agency to make up for the ways in which aides were generally not valued, including their low pay, and their exclusion from meetings.

When the veteran Hometowneer in the excerpt above said that they “value the information [the aides] provide,” this was contradictory to the aides’ exclusion from team meetings. If their information was valued, then why were they not included in the team meetings? She proceeded to give an account for this, when she said that they had not been able to work it out “logistically,” and that this was “unfortunate.” Her statement of appreciation, that they “could not do all of this without [the aides]” was her attempt to make up for the other ways in which they were unacknowledged.

This lunch was an unusual event at the agency, not only because it was part of an appreciation week. It was atypical because it involved *all* of the front-line practitioners of the organization (as well as management and office staff) in one meeting. They had meetings of management, meetings of office staff, meetings of home health aides, and team meetings. But they did not have scheduled meetings for all of the employees of the organization. This meant that there was more diversity in this gathering than in other more regularly occurring ones. And in accordance with the “homophily principle” (McPherson et al. 2001) – that similar people tend to associate with each other – the employees at this lunch sat with people like themselves. Since the people who worked in similar



positions were also likely to be similar in regard to certain sociodemographic characteristics, this went beyond divisions by occupational position. The workers were separated into homogeneous racial-ethnic, social class, and gender (though nearly all of them were women) groupings.

There were of course those who engaged in interaction with persons outside their racial-ethnic and/or social class grouping, but the conversations I observed contained awkward moments. A good example of this was the interaction I described above between a nurse, and an aide who mistakenly called her by the wrong name. This nurse had good intentions when she told the aide, “I get you all mixed up all the time.” She used what Goffman (1959) called a “protective practice,” in an effort to defuse the interactional disruption the aide had made. But this was an awkward moment because, as most of the aides were Black women, the “you all” sounded like “you Black women.” And when the veteran Hometownner announced that the aides’ perspectives were “valued” but then had to give an account for why they were absent from the meetings, this was also awkward interactionally.

When some of the social workers and nurses pushed the aides to line up first for food, this was embarrassing for many of the aides. Their body language showed reluctance. They did not run to the front of the line with pride; they instead were prodded there, and walked slowly. Those nurses and social workers who pushed the aides to go first were acting with a lot of familiarity with people whom they did not know very well. For instance, one of the social workers said to an aide, “Come on, Mama.” The aide turned to her, looked quizzically, and

said, “Mama?” The social worker said, “You’re a mama. You have a son.” The aide responded, “I have three children.” “Yes, go eat,” said the social worker in reply. This was yet another example of an awkward interaction across not only occupational, but also racial lines.

### **How Hometowners Benefited by Having an Inclusive Team Approach**

Considering the awkwardness of the interactions described above, one might wonder why Hometown had nurses’ aides on their staffs at all, much less included them in the rhetoric of “teams.” Placing Hometown Hospice in its broader historical context may help elucidate this. The modern hospice movement was founded primarily by middle class white people. American hospice organizations have continued to attract such groups as staff members. Modern hospices have also received attention for caring primarily for *patients* who are white and from middle-class backgrounds (Abel 1986). Over time, however, their patient base has moved away from such demographic groups (Beresford 1997).

In the past, having white, middle class (volunteer and professional) staffs was consistent with hospice organizations’ primary patient base. Now, however, with increasing racial/ethnic diversity nationally (U.S. Bureau of the Census 2000), as well as increasing competition for patients (Beresford 1997; Mahoney 1997), hospice organizations need to attract patients beyond their original base. Having only middle-class white staff members makes less sense for them as an organization than it used to. Therefore, beyond the fact that Hometown’s home health aides provided personal comfort to patients, they also served to diversify

the care staff, both by race and social class. In this way, having them as part of the staff theoretically benefited the organization.

The aides did not have to be directly employed by the agency, however. They could have been contracted out. But, Hometowners set themselves apart from other “home health agencies,” the very sites with which they would have needed to contract. They criticized the work of aides in such agencies, as well as in residential facilities. By employing aides themselves, Hometown had the benefit of their labor while maintaining a sense of superiority over home health agencies. Hometown management could also directly control the aides’ work, without the contracting agency as liaison. They could control the number of visits the aides made, the tasks that they did, and their pay. Therefore, it was in their best interest to hire them directly.

Professional Hometowners were not only proud of their team approach and its inclusiveness, they were also proud of the diversity of their patients. The social work manager said during our first meeting that it would be “contrary to [their] mission” to turn away any patients who were hospice-appropriate. She made it very clear that they did not discriminate. And the National Hospice Foundation’s web site says clearly, “Hospice services are available to patients of any age, religion, race, or illness.” The social work manager said that to turn away patients would be bad for their “public relations.”

Several workers in their interviews discussed social class diversity among their patients, without solicitation. A chaplain said she had had patients “everywhere from the political muckety-mucks to the tobacco shack.” A social

worker said that she had worked with “wealthy” families and that she had worked “out in the boonies with Black famil[ies], low education level, and no money.”

One of the chaplains made it clear in her interview that she had served patients of a variety of different religious backgrounds, and that she wanted to have more patients who were not from Judeo-Christian backgrounds. Generally, they made it clear that they had patient diversity.

Hometown promoted an image of inclusion, through their team rhetoric and their discussion of patient diversity. They said that their team approach was inclusive, and that anyone was welcome to receive their care. In an increasingly competitive health care environment, these were in their best interest.

Hometown’s mission statement stated that their care provision was through “an interdisciplinary team approach that [was] professional and compassionate.” The rhetoric of inclusion allowed them to seem “professional and compassionate,” despite exclusionary behavior that might appear otherwise.

#### *How Nurses in Particular Benefited from the “Team Approach”*

It appears that the nurses in particular benefited from the agency having a “team approach” to care. In the dominant medical model, doctors are the primary authority figures, with nurses below them in the hierarchy. But in the medical model, the goal is cure: the doctors’ specialty. In hospice, the goal is comfort: the nurses’ specialty. Though doctors’ referrals are required for patients to be admitted to hospice, and doctors have the final say on changes in their patients’ care plans, doctors were not as actively involved in the patients’ care as the nurses at Hometown.

Full-time RNs were considered “case managers,” the highest status members of the care teams. They were in charge of the most valued aspect of patient care: physical comfort. There were certain tasks that only nurses were allowed to do. These included: giving medications, setting up IVs, changing wound dressings, and setting up oxygen. These tasks were referred to as “skilled.” This allowed nurses to lay claim to aspects of the work that the aides (and other team members) were not allowed to do. Indeed, maintaining exclusive rights to these tasks is one way in which nurses in general have sought professional status. By default, nurses’ aides’ work is defined as unskilled and menial (Nakano Glenn 1992).

Another indication of their higher status was that nurses were required to pronounce every Hometown death. Even if an experienced aide, social worker, or chaplain was present with a patient when s/he died, none could pronounce the death. The death pronouncement was nearly a sacred rite, as it officially transformed the patient from “alive” to “dead” in Hometown’s documentary reality.

Nurses also had primary control over patients’ care plans. Nurses were the primary spokespeople for patients, as well as the liaisons between the patients and their doctors, and the members of management (including the consulting physician and pharmacist). Other members of the team were supposed to update the nurses on any changes in the patients. When I asked social workers, chaplains, and aides about communication among team members, their responses varied, but they all said that they talked with the nurses the most. The home

health aides also had to get nurses' permission to change any aspect of their care duties. The following excerpt from an interview with an aide shows this aspect of their work:

Molly: So who determines how many times you visit people?

Kecia: The nurse.

Molly: And then can you change it?

Kecia: Well, we can request. Because if I'm going every day and they don't want a bath every day, I can tell the nurse, "this patient, they don't want a bath every day" and they'll reduce it. Or either if I'm going three times or twice a week I can say "this patient needs a bath every day" and they can increase it. (Kecia, p. 36)

Aides could not change their care plans or their frequency of visits without the nurses' permission. Aides also had to continue to care for patients even if they requested that the aides stop coming, until they got permission from nurses to do so.

Whereas in conventional medicine, nurses are supervised by doctors, in hospice, nurses are generally not supervised (Mor 1987). Being case managers of patients who are in their own homes gives nurses autonomy. This is theoretically better than working in a hospital or doctors' office, where the physician is present in the place of care. Nurses at Hometown had authority as well, as described above. In fact, nurses also evaluated aides on a regular basis. One of the aides described this, saying "They have a check list. I think it's three pages. She observes me and then reports back to my supervisor."

With the team approach, the nurses could also relieve themselves of particular duties. For example, having home health aides on the teams helped

nurses. Nurses' primary job expectation was to provide patients comfort, and this would have been difficult to accomplish if patients' personal care needs were not met. Having aides on the teams meant that they were responsible for personal care tasks, so the nurses did not have to do (as much of) them.

With the team approach, the nurses could also do less emotional counseling with patients. They could draw in the social worker, chaplain, and/or volunteers to do so. During the nurses' meeting with the Executive Director that I observed, one nurse said with a sigh, "I think a lot of what we do is emotional support and counseling." She suggested that social workers assigned to the patient introduce themselves during the admission (the very first visit with the patient) rather than later, when their services were often refused. Her reasoning was that "they spill their guts during the admission," and therefore could feel a closeness with a particular social worker before deciding whether or not they would accept social work services. This nurse didn't want to deal with patients "spill[ing] their guts," because she saw that as the social workers' job. A team approach to care helped nurses avoid having to do even more emotional counseling.

During one nurse's report at a team meeting, the nurse said that the patient was doing "grief work." She said, "He's had these dreams. In one of them he dies. In another he gets treatment." Then, she said, "I think unfortunately now I'm doing social work stuff." This last statement shows that she recognized the difference between nurse work and "social work stuff." Having a social worker

on the team theoretically allowed her and other nurses to have fewer such discussions with patients.

A veteran Hometown worker was revising the training for new nurses during my tenure there. She said in her interview that she was socializing new nurses to the team approach:

I say to these new nurses, “You’re not alone. You’re working in a team. You don’t have to do this all by yourself. Call the social worker. Call the chaplain. If there’s a volunteer, call the volunteer. Pull in these folks. You’re not out there by yourself. Do not think that you’ve got to have all the answers. Be a team player.” (Connie, pp. 32-33)

She was encouraging the nurses to flesh out the team. She wanted nurses to take advantage of the benefits offered to nurses with the agency’s team approach.

In sum, having a team approach to care gave nurses more autonomy and authority than is typically offered in conventional medicine. Such an approach also allowed nurses to relieve themselves of particular duties while simultaneously claiming ownership of certain higher status jobs. Generally, the team approach to care appeared to particularly benefit nurses, at Hometown.

### **How Professional Hometowners Benefited From the Aides’ Exclusion**

Those in supervisory positions at Hometown gave accounts for why aides were included on teams but excluded from team meetings. For example, the social work manager said that aides have too many patients to see and that is why they could not come to the meetings. Similarly, the pharmacist said during the appreciation lunch that they had not been able to work out inclusive team meetings logistically. These were the spoken reasons given, but there were



unspoken reasons as well. Members of the professional staff benefited in several ways from excluding the aides.

### *Maintenance of Homogeneity*

As I discuss above, the social categories of race, education, and occupational status were intertwined at Hometown. This is not unusual in workplaces throughout the country, but it is particularly common among health care workers. Historically, for instance, white nurses tried to improve their status by separating themselves, in training and employment, from Black women (Cancian and Oliker 2000; Kalisch and Kalisch 1995). And by the middle of the twentieth century, there was in place a firm hierarchy in the nursing labor force, where nurses, with more professional training and authority, have enjoyed higher status and pay than nurses' aides (Nakano Glenn 1992; Glazer 1991). From the beginning, this segmentation has involved not only status, training, and pay, but also race (Nakano Glenn 1992). Though at Hometown those with professional status included more than just the nurses, the segmentation between the two groups of workers is a contemporary illustration of a historically produced phenomenon.

Hometownners did not explain the aides' absence from meetings in terms of homogeneity. That would not have been socially acceptable. But those who attended the meetings benefited from not having the aides there. I mentioned above that my data illustrate the homophily principle – that people tend to surround themselves with people like themselves, on a variety of characteristics. Indeed, others have suggested that people are *more comfortable* interacting with

people who are like themselves (Mazumdar 1995; Goffman 1973). People who have salient characteristics in common with each other have a certain understanding of each other, and therefore, keeping a group homogeneous allows for greater interactional comfort. I said above that there was awkwardness in the interactions across racial and professional lines that I observed at the home health aide appreciation lunch. By not having aides at the meetings, the white, college-educated professionals could largely avoid interactions with people who differed from themselves in terms of race, education, and professional status. They could assume that any disruptions in interaction were not caused by tension in regard to such potentially salient characteristics.

Hometown Hospice itself, like any workplace, is a set of social spaces within which occur patterned interactions. Since the home health aides did not have office space in the agency and were not included in the team meetings, Hometown was largely a space for interactions among white, middle-class people. Feagin and his colleagues (1996) write about Black college students' experiences as minorities at predominantly white schools. They refer to such college campuses as white spaces. They write about overt hostility and other forms of white racism targeting black university students. Hometown Hospice also constituted white space, but this was not shown with overt racial hostility. It was white space in the way that so many middle-class workplaces are: with virtually all white people, and the luxury of assumptions about being one of a group of like-minded people that accompanies that racial homogeneity. Whether or not assumptions about similarities between white people can be empirically

corroborated, it is more comfortable to be amongst people who are like oneself, particularly in regard to such a historically salient characteristic as race.

Higginbotham and Romero (1997) write of the tensions that can arise when working-class people and people of color enter formerly middle-class and white spaces. Indeed, they could be discussing Hometown's situation in particular in the following statement, "When people move out of their previous prescribed roles and come together in new ways without their old scripts, there can be tensions and problems" (10). The role of home health aides would indeed be changed with their inclusion at team meetings, and this inclusion would indeed require team members to "come together in new ways." This possibility for tension was avoided with the aides' exclusion.

#### *Exclusion of Aides' Interpretations*

Those in attendance at the meetings not only differed from aides in terms of race and professional status. They also differed in the amount of time they spent with patients. Aides generally spent more time per visit with patients, and visited patients more often, than other team members. And the aides were thanked and congratulated for talking with patients during the appreciation lunch. This sent the message that they should continue to do so, as part of their job. Along with these conversations came information, and knowledge about the patients. Their knowledge about patients was arguably more comprehensive than the information the other team members had. It is likely that their role in the meetings would go beyond the aforementioned "problems."

To be included in the meetings would send the message that their knowledge about patients, and their interpretations of what was happening with them, were valid and important. However, their training was shorter in duration than those of the professionals in the room. If the aides' knowledge and interpretations were valid, this might threaten the legitimacy of the professionals' training. In other words, without the aides there, the professionals could maintain their "cloak of competence" (Haas and Shaffir 1977). Had aides been able to discuss their own knowledge in the meetings, there may have been some incongruity between their interpretations and those of the professionals in the room. Through the aides' absence, this possibility of undermining the higher-status staff members' professional authority was avoided.

I observed the following interaction in a team meeting that reflects the preclusion of disagreement between aides and professional front-line staff:

Social worker: [The nurse] got a voicemail from the home health aide about some physical abuse in the household. We'll watch for that but I'm kind of shocked. We've seen no signs of that at all.

Facilitator/ Social work manager: Who said it?

Nurse: The aide. Apparently the patient got combative and the daughter said "do I need to get physical?" But there's no evidence of bruising.

Social worker: If it's happening, I think I'll be shocked because there are no telltale signs. I also went unannounced to see if I'd see anything. She was pleasant, and watching TV.

Nurse: She's talkative.

Social worker: I gently asked about it. I was vague, saying, "Are you afraid of anything?" If it's happening, I'd be surprised. (Notes 28, pp. 7-8)

In this excerpt, the nurse and social worker disagreed with the aide's construal of abuse between a patient and her family member. The aide was not present at the meeting to talk about any indication of abuse in the household. Instead, her thoughts were filtered through the nurse and social worker, who proceeded to dismiss her interpretation of the situation in the meeting. The professional front-line staff members agreed with each other that a claim of abuse was unfounded. Any possible tension arising from disagreement was avoided with the absence of the aide from the meeting.

During a subsequent discussion I had with this aide, she mentioned this situation without my solicitation. She was discussing dementia patients in general and their varying behaviors, when she said the following about the very same patient discussed above:

One time, she was not out of bed. She was on her knees and throwing punches. Fortunately the niece backed up and so did I. I cannot proceed under such conditions. I called the RN and said, "It's obvious to me that physical abuse has been used in the past." The niece outweighs you and me. The patient is as fragile as can be. I insisted [that they look into it].  
(Notes 32, p. 25)

The aide felt strongly that this situation was abusive. Yet she was not able to plead her case in the team meeting. Instead, others voiced her concerns and dismissed them.

Another disjuncture in this case between the professional front-line account and the aide's was in the reference to the primary caregiver of the patient. The nurse and social worker, who saw this family relatively infrequently, referred to the caregiver as the patient's "daughter," while the aide, who saw them several

times a week, correctly referred to the caregiver as the patient's "niece." This is admittedly a more mundane issue. However, any awkwardness that may have arisen from a lower-status person correcting a higher-status person was also avoided with the exclusion of aides from the team meetings.

### **Why the Aides May Not Have Pushed for Inclusion**

#### *Their Definition of Work*

When I asked the aides whether they wanted to come to the team meetings, each one said she would, but that she was too busy. The aides did not seem very bothered by this. They may have anticipated not feeling comfortable in a setting where they would be treated as status inferiors. There are other reasons why they may not have pushed for inclusion. In this section, I discuss several such explanations. First, the aides did not appear to define the meetings as "work." Work, to them, meant seeing patients. When they said they were "too busy," or that they did not "have time," it was because they were seeing patients.

The following excerpt from a conversation with an aide illustrates this perspective on work:

Betty: We don't go to team meetings. We're too busy working.

Molly: Would you like to go to team meetings?

Betty: I'd love to, but I'm too busy seeing patients.  
(Notes 32, p. 23)

Other aides made similar comments when asked about this issue.

The fact that the aides did not have office space in the agency contributed to their definition of work as seeing patients. A few aides joked that their cars

were their “offices.” This makes sense, as their cars were where they spent their time between patient visits. They did not come to the main office except to pick up supplies, turn in their activity log sheets, or attend periodic home health aide meetings. They rarely socialized in the office.

The more professional front-line staff, on the other hand, appeared to have a broader definition of work. Their work involved not only seeing patients, but also spending time at the office. They had office carrels where they used their phones and did paperwork. And they interacted with each other there, during various meetings and more socially. Meetings appeared to be included in their definition of work; it was not time taken away from it.

#### *Pay Differentials*

There was at least one other reason why the aides might not have pushed for inclusion in the team (and other) meetings. And that was pay. Part-time home health aides at Hometown got paid less for attending meetings than for visiting patients. Part-time workers got paid a certain amount per meeting, and that was less than the amount they were paid per visit. It was not in their best interest financially, therefore, to attend more meetings than they had to (or to push to be included in such discussions). The full-time aides were also not monetarily encouraged to push for more meetings. Their pay was called a “salary,” but they only received the salary if they completed 25 to 30 patient visits a week. Therefore, it was in their best interests to spend as much of their work time seeing patients as possible, and attending meetings would cut into that time.

### *Comparison Referents*

Another reason aides may not have pushed for inclusion involves their perceptions concerning the fairness of their treatment. These perceptions may depend upon their chosen point of comparison (Major 1987). That is, even if treatment is unequal, it can still be perceived as fair, with the right comparison referent. This theory has largely been used to explain why women in heterosexual couples who do a disproportionate amount of housework tend not to see the distribution as unfair (Thompson 1991; Sanchez 1994). The finding is that women tend to make within-gender comparisons rather than between-gender comparisons. As long as women are comparing themselves to other women (and their partners to other men), they are less likely to see their situations as unfair.

The aides' situation at Hometown was analogous. The aides at Hometown were clearly treated unequally. They were paid less than the other front-line workers, they had less autonomy and authority, and though they were included in the rhetoric of teams, they were excluded from the team meetings. However, these were in comparison to *the other front-line workers* of the organization. The aides did not compare themselves to them; instead, they compared their situations to those of *aides at other types of organizations*. Indeed, this may have been encouraged by the fact that they did not interact regularly with the professional staff, in team meetings or otherwise. Ultimately, they saw their situations as better, and therefore unworthy of complaints of injustice.

One aide had worked at several nursing homes before beginning work with Hometown. I asked her which she liked better, and why. Her response:



Kecia: I like it [here] better because you have more freedom. In a nursing home, there's always someone there. Plus, going from patient to patient, in between, in the car, you get a chance to think, and get a break, to prepare yourself for the next patient. Like if it was a difficult patient or a patient died or something. It gives me a chance to get ready to see the next patient.

Molly: Right, rather than going from one room to the next, like in a nursing home.

She nods.

I ask how many patients she sees in a day.

Kecia: Five or six.

Molly: Is that a lot?

Kecia: Not compared to a nursing home. You might see 14. (Notes 31, p. 40)

In comparison, the work Kecia did at Hometown was better than the work she had done at various nursing homes. She had less supervision. (At nursing homes, "there's always someone there" overseeing her behavior). She saw fewer patients. And she had time in between patients to re-group and prepare.

Kecia also said that she got closer to patients at Hometown than at nursing homes she had worked in. She offered the following as explanation:

In the facilities you have 15 minutes tops for your patients because you might have one [aide] on a hall and that's 20 something patients. You've got to try to get all those patients up, dressed, and whatever, and you really don't have time to get close to them. You're spending the whole time just taking care of personal needs that you can get to. (Kecia, p. 15)

Indeed, ethnographic research on the work of nurses' aides in nursing homes corroborates this. Foner (1994) and Diamond (1986, 1990) discuss in detail the fast pace expected of such workers. They are expected to tend to many patients,

quickly, and to keep track of the personal care tasks that they do. Any talking with the patients is seen as “loafing” unless it is being done in conjunction with the required bodily tasks. Aides are highly supervised, both by nursing supervisors and administrators. And the work involves little or no autonomy.

Nursing homes were not the only point of comparison the aides at Hometown used. Another aide had done clinical work at a hospital as part of her training as a Certified Nursing Assistant. She described her work as follows:

I was in the hospital from 7 am till 3 Monday through Friday. We had a 15 minute break in the morning, a 30 minute lunch, and a 15 minute afternoon break. If you remember to take it. It's pretty hectic in a hospital. (Notes 32, p. 33)

She went on to say that she had “been in enough hospitals” to “see what they were doing”:

Their pay is crappy, it's grunt work. The patient load is so high. They have high turnover. What you do is physical. ... I decided early on that I would not work in a hospital, or assisted living, or a skilled nursing facility. I wanted home health, and [then decided on] hospice.

In comparison to her experiences at a hospital, and to what she had observed of other nursing assistants in hospitals, the treatment she was receiving at Hometown was better.

Though the aides' treatment may not have been equal to that of the more professional front-line staff's, the aides did not describe it as unjust. One reason is that they did not primarily compare themselves to the other front-line workers at Hometown. Instead, they compared their work to the work of aides in other organizations, such as nursing homes and hospitals. And in comparison, their situations did not seem inequitable enough to warrant complaint.

The work of nurses' aides at Hometown involved fewer patients per day and more flexibility than such work at nursing homes or hospitals. And these appeared to be important aspects of their day-to-day labor. More important, in fact, than whether there was clear inclusion of aides on Hometown's caregiving "teams." Even being said to be part of a team sounds better than no team rhetoric at all, regardless of whether it amounted to anything materially.

### **Conclusion**

Hometown Hospice's team approach to caregiving allowed them to claim uniqueness and superiority in comparison to other providers of care to terminally ill people. When they described their team approach, they emphasized its inclusiveness. However, in practice, this approach was not as inclusive as they made it appear. The home health aides at Hometown were excluded from the one legitimized gathering of team members: the team meetings. As I show above, there were further separations between the aides and the other team members that called into question the true inclusiveness of the Hometown teams.

There was evidence that Hometowners recognized the contradiction between inclusive rhetoric and exclusionary reality. One attempt to manage this contradiction was the provision of a home health aide appreciation lunch. I analyze this lunch in this chapter, and show how the awkward interactions across race and professional status that occurred there exemplify the possible tensions that were avoided by the exclusion of aides from the team meetings. The professional front-line caregivers also benefited from this exclusion because the aides actually spent more time with the patients than they did, and any possible

disjunctures in the interpretation of events were precluded by the aides' absence. The aides themselves did not push to be included in the team meetings. Though their treatment was unequal, they did not appear to see it as unfair. Along with the benefits afforded the professional staff, this explains the continuance of the clear contradiction between rhetorical inclusiveness and exclusionary reality concerning the team approach at Hometown Hospice.

In the next and final chapter, I weave together the major points of all of the previous chapters in this dissertation, into a summary argument. I argue that Hometown Hospice was not as different from conventional medicine as its underlying alternative philosophy suggests, and I explain why. I then use my analysis to draw parallels between the dilemma facing workers in hospice organizations and those in other settings, both within and outside health care.

## **Chapter 6**

### **Conclusions**

Before I began studying Hometown Hospice, I had a romanticized view of hospice work. I imagined hospice workers spending tremendous amounts of time with dying people, in efforts to help them die comfortable, peaceful deaths, in their own homes. I went into this study with the utmost respect for those who work in hospice. I admired them and wondered how they could do the work of caring for the dying.

I still respect and admire those who do hospice work. But I no longer romanticize it. I now see this work as fraught with dilemmas, both practical and ideological, like most any other work. I see the constraints that hospice employees must work within. And I see some of the consequences, both intended and unintended, that result.

The workers at Hometown Hospice followed a unique philosophy that set them apart from other providers of care to the dying. But though there are differences between hospice and work with the dying in a hospital or nursing home, it is clear from this study that the work done by Hometowners was not as different from conventional medicine as they set out for it to be, or as they suggested it was.

Indeed, each analytical chapter in the dissertation has this theme running through it. As I show in Chapter 2, though the hospice movement originally began as anti-bureaucratic, hospice work became rationalized over time.

Hometown Hospice illustrated this shift in several ways. The process of rationalization resulted in work that was not different enough from that of conventional medicine to deem it a true alternative. In Chapter 3, I discuss how the dominant medical model was evident in Hometowners' work, despite the commitment to holistic medicine in the hospice philosophy. Again, the presence and influence of the dominant medical model reflects a not-so-different "alternative." In both Chapters 3 and 4, I discuss some of the unique challenges that arise in hospice work. These challenges constituted part of the constraints working against Hometown Hospice being really different from conventional medicine. And in Chapter 5, I show how they perpetuated inequalities despite their use of an interdisciplinary team approach to caring for the terminally ill. Again, though their team approach was unique, they missed opportunities to really set themselves apart from other care providers.

There are several ways in which hospice work *is* different from the work of medical practitioners in hospitals and other facilities. For instance, all of the patients are considered terminally ill in order to be receiving the care, and the work primarily takes place in people's homes. The philosophy of care is also specific to hospice. In this philosophy, members of an interdisciplinary team provide care to terminally ill patients and their families. Patients receive individualized care that is palliative and holistic, and family members receive the support that they need. Having an interdisciplinary team, focusing on palliative care rather than curing, offering purposeful support to families, and giving holistic care rather than solely medical treatment, all make the hospice philosophy unique.

But in order for hospice to be a true alternative to conventional medicine, this philosophy would need to be fleshed out in a number of ways. First, the care would need to be truly individualized for each patient. Second, all aspects of holistic care (physical, emotional, and spiritual) would be given equal legitimacy. Third, patient comfort would be an actuality for all. Fourth, the interdisciplinary team would be inclusive, despite differences of race and professional status.

Though Hometowners followed a philosophy that differed from that of conventional medicine, their practices were conventional in many ways. In this chapter, I discuss what kept them from being more different. I argue that though their philosophy calls into question the sole reliance on scientific rationality in modern society, they are tied to conventional medicine through Medicare certification and accreditation by the Joint Commission of the Accreditation of Hospitals. These regulating bodies are run by people following principles of scientific rationality. I argue that various ties to the conventional, whether forced or chosen, result in practices that are then not as different from the conventional as an alternative philosophy suggests.

I illustrate this argument with my own data from Hometown Hospice, and through prior case studies of other health care sites. I also discuss the dilemma between philosophy and expected practices that is faced by at least two entirely different groups: alternative public school teachers, and organic farm practitioners. My analysis of what is occurring at Hometown Hospice may help us better understand the dilemmas people are facing in other settings as well.

## **Questioning the Sole Reliance on Scientific Rationality While Working Within Conventional Medicine**

Hospice workers follow a philosophy that questions the sole reliance on scientific rationality in modern society. Yet, as a result of the process of rationalization that I discuss in Chapter 2, Hometown and other hospice organizations have tried to do so while working *within* the confines of conventional medicine. This means following the regulations set by Medicare (which provided the bulk of Hometown's funding) and the Joint Commission on the Accreditation of Hospitals (which certified them and made them appear legitimate). Since the great majority of hospices are certified for Medicare reimbursement and/or accredited by the Joint Commission (National Hospice and Palliative Care Organization, 2000), Hometown follows the hospice norm in this regard. Below, I discuss the ways in which conventional regulations constrained Hometown practitioners' ability to do something really different.

### *Hospice-Appropriateness*

Hometowners were forced to follow the rules of "hospice-appropriateness" set by Medicare. These require that patients are referred by their own primary physicians. Primary physicians have to attest that in their educated opinion, the patients have six months or fewer to live, and give assurances that they have decided to end curative treatment. Primary physicians remain primary throughout the patients' stay with hospice. They must approve each change in patients' care, whether it concerns medication, a move to a facility, or a change in frequency of practitioner visits. Also, in order for those who are admitted as



Hospice Medicare Benefit patients to get their medications paid for, each drug must be directly connected to their primary diagnosis as articulated by their physician.

The above points to a “double constraint” for hospice organizations like Hometown which rely on the Hospice Medicare Benefit. Not only are they constrained in general by the various rules set up by those who created this benefit, they are also continuously constrained by the inextricable tie to conventional medicine that is the primary physician. Primary physicians have been trained to follow the dominant medical model, rather than the more holistic philosophy of care that hospices espouse. They are likely to have a limited knowledge of palliative medicine, while this is the niche that professional hospice practitioners have carved for themselves. They are likely to push curative treatment until death is imminent or until it occurs, which goes against the hospice philosophy. And they tend to be more resistant to the ongoing use of intensive pain treatment than hospice practitioners themselves. This continuous tie to primary physicians meant that Hometown practitioners were limited in how alternative they could be, with patient care.

Hospice appropriateness is not solely determined at the patients’ admission to hospice. It has to be constantly reevaluated, to justify keeping patients in their care. Before the end of each “benefit period,” primary and consulting physicians have to offer *medical* evidence that the patients appear to have six months or less to live. This requirement flies in the face of the holistic approach to caregiving that sets hospice apart from conventional medicine. At

Hometown, particularly at the team meetings, more value was placed on medical evidence than spiritual or emotional components of patients' progress or decline. The unique opportunity that hospice organizations have to give equal legitimacy to medical, emotional and spiritual aspects of care was lost at Hometown, at least in part because of this requirement set by Medicare.

### *Documentation Requirements*

Hometowners were also required to follow rigid rules of documentation set by the Joint Commission. At a minimum, they had to fill out forms for each admission, each patient visit, each patient discussion at a team meeting, and each death. At each stage, they had to discuss the different "problems" that were listed for each patient, the "interventions" to address the problems, and their resultant plan for the future. The care plans themselves were not individualized.

As one of the social workers put it in our interview, the practitioners were required to be "problem-oriented" in their documentation. She instead preferred to be "goal-oriented" in her thinking, and in her care. So though they were forced to discuss problems and interventions in the documentation, the kinds of things she was focused on were really separate from that. She talked about being "present" with patients and families: "really absorbing what they're saying, facilitating them saying it, and identifying it and helping them find meaning in it." She talked about offering support, helping the patient and family determine their goals and then helping them achieve them, or put them to rest. Yet these were not captured on paper. They were speciously coded as "interventions" for such problems as "coping difficulty family." Instead of freely writing what they did

and how, their paperwork was focused on somewhat strictly defined problems and interventions.

Based on the audit conducted by the Joint Commission, the practitioners were discouraged from discussing anything in the documentation that could be deemed extraneous to the problems, interventions, and plan. So though the practitioners described the “extra, out of the box stuff” they had done for patients over the years as defining hospice, such as bringing baked goods on their birthdays or taking them on special excursions, there was no place for that in their documentation.

Throughout my tenure with the organization, several practitioners noted the rigidity and redundancy of their paperwork. It was as if they did what was expected of them in terms of documentation, but that it was not meaningful for them. A lot of what they really did for the patient and family got left out of the documentary reality. They were not invested in the paperwork they wrote; it was repetitive, non-creative, and non-fulfilling work. Since there was so much paperwork for them to do, this is not a minor concern. Had the practitioners been encouraged to document the aspects of their work that they deemed important, in whatever reasonably structured way they chose, this would have sent the message that what they did with patients was valued. Rather than encouraging cookie cutter care through their documentation requirements, this would be tantamount to encouraging creative, unique care for each patient from the practitioners: something that would be truly alternative.

### *Team Meetings*

As part of the Hospice Medicare Benefit, practitioners are required to meet and discuss each patient in their care at least every two weeks. These “team meetings,” as they are often called, offer an opportunity for hospice work to stand out as distinctively communicative and team-oriented. Past literature on hospice idealizes team meetings, as providing strong interpersonal support while encouraging greater autonomy and participation in decision making than is typical in conventional medicine (Mor 1987); and as offering “a sensitive, weekly-monitored coordination and alignment of [a front line worker’s] performance with the performances of the various other members who are also seeing a patient and family” (Ward 1998, p. 56). But in actuality, at least at Hometown, such opportunities were stifled.

Regular meetings of interdisciplinary practitioners are particular to hospice organizations (Mor 1987). These team meetings could be times of support and exciting exchange, where patients are really tried to be understood, and where workers can let their true feelings out. Instead, at Hometown they were seen as repetitive, too focused on medical issues (to the exclusion of emotional and spiritual ones), and unhelpful. Though they were lighthearted, as I discuss in Chapter 4, the patient discussions were abbreviated, and, congruous with the paperwork, focused on problems, interventions, and plans for the future. There was virtually no time for them to discuss any “out of the box stuff” at the meetings. In fact, there was less discussion at the meetings than there was the

giving of reports, particularly from nurses. Most of the “discussion” centered around issues of hospice appropriateness, as I discuss in Chapter 2.

This was their chance to “debrief” as one chaplain put it, yet several practitioners spoke of the lack of support they received. The practitioners sounded as if team meetings were a necessary part of their work, but not something that they embraced and looked forward to. They had to give reports and write down the reports that were given, in their required jargon. One of the chaplains said to me during our interview, “We do the best work when we allow ourselves a little extra time and do tell some of the stories. Because that’s when the rich stuff comes, and that’s when you hear those not just clinical things that we all need to know. Plus it helps us.” Yet the facilitator and other members of management frequently said to the front-line practitioners at the meetings, “No stories. Just the facts.” They were concerned about being efficient, while fulfilling the requirements set by Medicare. This was yet another opportunity to make hospice work truly different from conventional medicine that was squandered.

#### *“Team Approach”*

Though their team approach set hospice work apart, there was at least one aspect of the work that was decidedly not different from that of conventional medicine: the perpetuation of racial-ethnic and class inequalities. As I discuss in Chapter 5, though they had a team approach to caring for the terminally ill, Hometown did not use the opportunity that offered to have inclusive, less hierarchical teams. The lesser value placed on the work of nurses’ aides at

Hometown was particularly evidenced in their exclusion from the regular team meetings of the organization, and their relative lack of decision-making power in comparison to the members of the professional staff. Instead of following a less hierarchical division of labor, which would really have been different, Hometown perpetuated the status differential between nurses and nurses' aides that exists throughout the health care industry.

In her study of nursing assistants in nursing homes, Foner (1994) offers some suggestions about how to improve their working conditions. She suggests that nursing assistants be included in treatment care conferences. She also recommends that nursing assistants' opinions be solicited when designing care plans. Aroskar, Urv-Wong, and Kane (1990), in their review of the literature on the care in nursing homes, also recommend involving nursing assistants in care planning. They suggest that this would bring greater "personal rewards" to these workers, and would in turn benefit the residents as well (289).

Interestingly, even in an article written to an audience of managers in the home-care industry, Schmid and Hasenfeld (1993) recommend that home care workers be given more responsibility. They argue that such workers should actively participate in meeting patients' needs. They cite research suggesting that this leads to increased "worker satisfaction, trust in management, belief in the equity of rewards allocation, positive attitudes toward the organization and low levels of turnover and absenteeism" (p. 47). This article is an attempt to benefit management more than workers. Yet the recommendations are similar to those given above.

At Hometown, nurses aides' input was not solicited in the creation of care plans. Aides were given care plans to follow, and any changes in those plans had to be approved by the case manager. In fact, some changes in aides' care plans, such as requests to increase the frequency of patient visits, had to be taken by nurses to the patient's primary physician for approval. Thus, part of the hierarchy that was evident at Hometown was placed upon them by their tie to conventional medicine.

Also, as I discuss in Chapter 5, with the exclusion of aides from the team meetings, homogeneity by race and professional status was maintained. Any tension that might have been caused by differences in how the professional staff and the aides interpreted situations, was precluded. Professional staff members' "cloak of competence" was sustained in the process. This could also be a reason why aides' input was not solicited in the creation of care plans. If aides' input was seen as just as valid as that of the more educated professionals, their legitimacy as experts may have been called into question. In the end, Hometown squandered an opportunity to make hospice work a true alternative to that in other health care settings.

### *Residential Facilities*

Hometown's contracts with various residential facilities represented a sacrifice of a key part of what makes hospice care unique: that it takes place in people's homes. These contracts also constituted an added tie to conventional medicine, in the form of the staffs of the facilities. Hometown workers gave up some of their autonomy by working in facilities, and therefore had even more of a

challenge in enacting the philosophy that made them unique. In particular, pain control, and physical comfort in general, were made more difficult by the added layer of staff. There were more eyes watching them, and more questions asked of them, by those who were trained – and working in – a more conventional system.

Also, as I noted above, the patients were not at home, nor were they necessarily surrounded by familiar people. These patients' family members, therefore, did not receive the same attention as they would otherwise have. Whereas when the patients were in their homes, the Hometown workers saw family members more regularly; when the patients were in facilities, these meetings were either of coincidence or they had to be planned. Therefore, they happened less frequently. In the end, they were constrained in accomplishing truly alternative care, partly as a result of the added tie to conventional medicine.

#### *Other Health Care Sites*

Hospice workers are not the only providers of health care who question the sole reliance on scientific rationality in philosophy but are constrained in practice. Indeed, any “alternative” (to various degrees) health care organization whose members choose – for any number of reasons – to engage with the conventional, are then constrained by that tie to the conventional, in following an alternative philosophy. Here, I briefly discuss two other health care sites where this tension has occurred.

Schneirov and Geczik (2002) conduct a case study of a “complementary” (alternative) medical clinic which existed as part of a prominent American hospital. In this clinic, “holistic” doctors and other practitioners offered



alternative health services such as herbal remedies, relaxation therapies, and acupuncture. Yet they had to do so within the confines of a conventional medical establishment. One consequence of this was that they were pressured to show that their treatments were indeed having the intended therapeutic effect on their patients. In order to do so, they were expected to conduct randomized, double blind, clinical trials – the sort that are acceptable to those in the biomedical community – to show that particular treatments were related to specific outcomes.

However, as the authors tell us, following an alternative medical philosophy meant accepting that desired outcomes may arise (and perhaps should arise) because of a combination of factors, including personal relationships between patients and their practitioners. Therefore, teasing out individual treatments to show that they are “effective” is not only difficult, but also going against the philosophy. The authors discuss how two of the practitioners in the clinic recently had a National Institute of Health grant rejected because they included too many variables in their study, without a sufficient way to disentangle the effects of each. They summarize the “bind” that alternative medical practitioners are placed in, if they are required to get grant money to show biomedical evidence of the effectiveness of their treatments:

“If they try to demonstrate a particular modality has therapeutic effects, they know they will have very limited success since this means treating alternative medicine non-holistically. But if they try to design a study to demonstrate the effectiveness of a holistic program of interventions, an approach that comes close to reflecting the philosophy of alternative medicine, no one will fund it” (210).

They were forced to either sacrifice their alternative philosophy or give up their tie to the conventional, along with the security and legitimacy that offers.

Kleinman (1996) studies a clinic she calls Renewal, whose members held an alternative, holistic medical philosophy. They indeed offered alternative “healing” services to people. They also practiced some unconventional customs during their time together: they hugged as part of their greeting, they sat in a circle to begin and end their meetings, and they talked about their feelings toward each other in a direct manner. But they also engaged in various conventionalities in order to confer legitimacy on themselves as an organization. These included having professional titles, following bureaucratic rituals such as Robert’s Rules of Order during meetings, and having committees who reported to the board. Engaging in these more conventional practices made them feel more professional and legitimate, but it also meant that their work with each other was not truly different from that in more conventional health care organizations.

Kleinman also argues that the people at Renewal were so attached to their “alternative” identity that they did not see how their practices served to perpetuate conventional inequalities. The division of labor at this small organization was relatively simple: “healing” practitioners, and office staff. The former were men and the latter, women. The office staff were paid much less, and deemed less important, than the practitioners. While the (male) practitioners were lauded for showing signs of femininity, the women in the organization were sanctioned for displays signifying conventional masculinity. So rather than being truly alternative, the gendered treatment of people in different positions reproduced

conventional inequalities. This is analogous to Hometown's perpetuation of racial and class inequalities, despite their use of "team" rhetoric.

### **Where Do Similar Challenges Occur?**

This dilemma of trying to follow a philosophy that questions scientific rationality while being expected to engage in practices that follow its principles, is not unique to those in hospice or other health care organizations. I now turn my attention to other arenas where people try to follow an alternative philosophy while working within a larger context of the conventional. Alternative public school teachers must attempt to follow alternative pedagogical philosophies within the confines of conventional education. Organic farm practitioners who follow an alternative agricultural philosophy must increasingly do so within the confines of conventional agriculture. I discuss how their philosophies differ from the conventional, and how they may be constrained in how alternative they can be, considering their contexts. I conclude with a summary statement that ties my argument together.

#### *"Alternative" teaching*

Alternative public school teachers, trying to follow alternative pedagogical philosophies while working within the public school system, are constrained in doing so. Educational policymakers, and state and federal legislators, tend to use a more conventional pedagogical model (Berry 1996). Those in American public schools are therefore required to follow rules and regulations which may contrast with their preferred philosophy. People with pedagogical philosophies differing from the conventional are variously referred to in the literature as "critical"

(McLaren 1994; Sullivan 1999), “radical” (Sweet 1998; Freire 1971), “progressive” (Bidwell et al. 1997), and “democratic” (Fischman and McLaren 2000). I use the blanket term “alternative.”

Just as the psychosocial model of health care contrasts with the dominant medical model (as I discuss in Chapter 3), alternative pedagogical philosophies contrast with conventional or mainstream pedagogies. Clearly, this occurs to various degrees. But rather than compare and contrast those who hold educational philosophies that differ from the conventional, I will refer to them in combination. Here, I sketch out the various components of an ideal typical conventional teaching philosophy as contrasted with more alternative pedagogical philosophies, according to the literature. My point is to show that alternative public schools which attempt to follow any of varying degrees of alternative pedagogical philosophies may be constrained in how well they can do so, given their context.

In the conventional educational philosophy, teachers are viewed as *the* keepers of knowledge in the classroom, while students lack knowledge. Learning is said to occur as teachers fill students with their knowledge, through lecturing. As Freire (1971) describes this “banking concept of education,” teachers are “depositors” and students are “receptacles.” This is a uni-directional and passive process.

The more alternative view is that teachers and students are both capable of teaching and learning. Both teachers and students have knowledge, and both can be useful for enhancing learning. Therefore, lecturing is avoided, in favor of

active dialogue among students, and between students and teachers. Through communicative dialogue and social activism, it is argued that students should develop a critical consciousness, rather than be passively filled with the content of teachers' narration (Long 1998; Freire 1971).

Following the conventional model, specific facts are taught, with the goal of students' remembering them. These facts are not to be questioned or challenged by the students (Giroux 1979). Learning is evidenced through accuracy of responses on class examinations and standardized tests. Students are vertically sorted based on the results of such examinations, thereby encouraging a competitive spirit among them (Galtung 1975).

In the more alternative view, rote memorization is eschewed in favor of critical thinking. "Priority is given to the development of students' conceptual understanding, skills in critical thinking and other aspects of higher-order mental process, and intellectual independence and skepticism" (Bidwell et al. 1997). Students are taught to think rather than memorize, and to dialogue rather than regurgitate. Instead of being discouraged from challenging the teacher, they are encouraged to do so, in the vein of communicative and thought-provoking discussion (Freire 1971).

In the conventional educational model, there is great social distance between the teacher as authority figure, and the student as subordinate. Students are expected to be disciplined and obedient (Graubard 1972), and to follow the standard rules, such as not speaking unless spoken to, raising one's hand to pose a question, and generally treating the teacher with deference. In the more

alternative view, the social distance between teacher and student is minimized. These teachers “subordinate conventional notions of classroom discipline to a more flexible classroom order that is designed to develop students’ cognitive growth and self-discipline” (Bidwell et al. 1997). Following an alternative pedagogy, teachers share power with students (Long 1998) or even relinquish power to them (Sweet 1998).

It has been said that conventional educational practices serve to perpetuate the status quo (McLaren 1994; Giroux 1979; Bowles and Gintis 1976; Freire 1971). Facts are taught as if they are apolitical and unchallengeable. Knowledge is presented by the teacher as if it lacks any historical, political or cultural context. As Giroux (1979) argues, “Classroom knowledge is often treated as an external body of information, the production of which appears to be independent of human beings.” The interconnections of knowledge, power, and ideology are absent; therefore, “facts” lack any political character. Students are not taught to think critically, reflect, or challenge what they hear. Instead, they are expected to follow rules that others have made, memorize content that others have chosen and planned, and accurately respond to questions on examinations that others have formulated. In this way, their education reinforces subordination in a stratified society (Galtung 1975; Freire 1971). Bowles and Gintis (1976) argue that conventional education not only reinforces stratification through the subordination of students, it also reproduces a hierarchical class structure within students themselves, thus allowing a capitalist production system to be perpetuated.

The more alternative approach seeks to subvert the status quo. Teachers using this approach, instead of taking factual knowledge for granted, treat it as tied to power and ideology. Rather than perpetuate a hierarchical system, they seek to minimize their authority in the classroom. Students and teachers are seen as equal participants who teach and learn together. Students are not expected to passively follow rules and “receive” knowledge. Ideally, students actively engage with the content of the course, think critically, and reflect, and also *act on* the knowledge through social activism (Sweet 1998). Even if social activism is not required in the course itself, the ultimate hope is that critically thinking, creative students are prepared to alter the structure of society when they leave school (Freire 1971). Teaching practices are “generated toward transformation of the larger social order in the interests of racial, gender, and economic justice” (McLaren 1994).

### Conventional Constraints

Practitioners in America’s public schools are not autonomous actors. They have to follow rules and regulations that are set by various players in the game of education. These include members of departments of education, and local, state and federal legislators. Teachers and administrators in America’s public schools are required to follow state-mandated curricula that dictate required courses for students (Graubard 1972). What teachers teach, and how they teach it, may also be blueprinted for them in a process of “scripting” that is popular in curriculum policies (Clune 1990, 267).

“Educational reform” has gone through many phases since the American public school system was developed. Since the 1980s, educational reformers in America have increasingly followed a business model, where “quality” is lauded (Johnston 1996) and “accountability” for teachers and administrators is emphasized. This, combined with a heightened focus on teaching “the basics,” has resulted in particular performance expectations for schools (Berry 1996). Federal and state legislators and departments of education have developed standards of performance as well as accompanying sanctions to see that those standards are met.

The “No Child Left Behind” legislation, which was signed into law in early 2002, is President Bush’s educational reform plan. With this law, states are required to set student standards for math and reading (and later science), and then test students’ progress toward those standards. Schools are given report cards that publicly show how well they are performing, based on their students’ results on standardized tests. Schools are expected to improve yearly. Those schools which continuously under-perform risk federal sanctioning.

As with welfare reform, each state implements this legislation differently, so it will be challenging to discuss its national effects. Here, I focus briefly on a school reform system which has received Bush’s seal of approval: North Carolina’s “ABCs” program. The “A” stands for accountability, the “B” stands for an emphasis on the basics, and the “C” is for local control of the work. Just as Bush has ostensibly given states control of discretionary monies, North Carolina has given its local school districts control over state funds.



In this program, students across the state are required to take end-of-grade multiple-choice tests. Students must achieve certain scores in order to be promoted to the next grade. And aggregate test scores from particular grades are compared to standards set by state officials. These measurements of school performance are made public in what are called “NC School Report Cards.” Every year, high performing schools are recognized with special school titles and monetary rewards for staff. The lowest performing schools receive less flattering designations, and they are required to welcome “state assistance teams” who help school staffs develop and implement plans to improve students’ test scores.

Critics have charged that such high-stakes testing serves to restrict the curriculum to those subjects and skills which are covered on the tests (Berry 1996). In North Carolina, for example, the ABCs program has encouraged teachers to focus on the state-mandated curriculum, therefore emphasizing reading and math to the detriment of social studies, science, and art (McMillan 1999). Also, multiple choice standardized test questions are more likely to test memorization skills than critical thinking. In fact, the now disbanded North Carolina Standards and Accountability Commission itself recommended that there be multiple assessments through which students’ knowledge is gauged, including tests of aptitude in communication, real-world problem solving, and teamwork (McMillan 1999). Such recommendations and criticisms have been ignored.

The educational reform system that has been enacted by federal and state governments has resulted in constraints that may work against grade school and high school those who are trying to follow alternative pedagogical philosophies in

their schools. Teachers are forced to vertically sort their students according to the accuracy of their responses on state-mandated multiple choice standardized tests. The threat of sanctions discourages teachers to teach any content that is not covered on such examinations. This not only excludes or limits coverage of particular subjects like social studies or art, it also leaves out the kind of content that alternative teachers wish to emphasize: that which connects knowledge with power and ideology, and that which subverts the status quo through critical thinking and doing.

There is some evidence that those working in alternative public schools are constrained in carrying out an alternative school philosophy. Chenoweth (1989), studies surprisingly successful San Francisco public alternative schools developed in the 1970s and 1980s. A charismatic superintendent had been instrumental in beginning the schools, and he and his administration used symbolic management to attract teachers and parents to the supposedly “alternative” schools. The author found that though they used the language of alternative, the curriculum and instruction at these schools was actually more conventional than alternative. He argues that the schools survived expressly *because* they were not much different from conventional public schools.

Powers (2002) conducts an ethnographic study of three California charter schools. These schools, which began to be popular in the mid-1990s, are public schools begun by interested parents, teachers, community members, or entrepreneurs, who want to create another option for students in their areas. Such schools must have a chartering agency and a board of directors in order to be

approved by local authorities (Yancey 1999). Though technically “unregulated,” charter schools are still held “accountable” for the performance of their students (Finn et al. 2001). In her analysis, Powers shows how those in the charter schools she studied tried to enact the educational philosophies in their charters. But to the extent that these philosophies differed from those of conventional education, the state and local educational policies constrained their efforts in doing so.

Though the parallel is not as strong, alternative teachers in conventional colleges also appear to be limited in how truly alternative they can be. Sweet (1998), in his review of two decades of *Teaching Sociology* articles, argues that the failure of college teachers to practice radical pedagogy is at least partly due to institutional constraints. These include criteria for tenure and promotion, which give priority to research publications in peer-reviewed journals, while minimizing, ignoring, or actively discouraging social activism. The practice of alternative pedagogy is also time-consuming. And students, who are socialized within conventional modes of education, are not typically comfortable with developing a critical consciousness, and/or participating in social activism. This affects their evaluations of alternative teachers and their courses, another element in considerations of promotion and tenure. Thus, criticizing the rationality of the educational system (to whatever degree) does not excuse one from following its conventional rules. This in turn constrains alternative teachers’ ability to offer a true alternative.

## *Organic Farming*

Just as Hometown Hospice workers tried to follow an alternative philosophy while working within the confines of conventional medicine, and some educators try to follow alternative pedagogical philosophies from within the confines of conventional education, organic farm practitioners are limited in how truly alternative they can be, while tied to conventional agriculture.

Since the early 1980s, the modern agricultural industry has encountered increasing criticism for its perceived damaging effects to the environment and to people's health (Beus and Dunlap 1990). In their widely cited 1990 article, Beus and Dunlap contrast the perspectives of those who advocate the practices of modern agriculture and those who oppose its sole reliance on scientific rationality. Their categorizations are ideal types, to be used to better understand the overall agricultural debate. Here, I discuss the basic components of these perspectives. I then focus on one type of alternative agriculture in practice, organic farming, and discuss how its practitioners appear to be increasingly constrained in how truly alternative they can be.

Beus and Dunlap (1990) summarize the views of the major advocates and critics of modern agriculture into six areas of contrast; I merge them into three here. The first concerns centralization. Conventional agriculturists endorse a highly industrialized method of food production, processing, and marketing of food, through large networks of people. They support large farms with few farmers. They believe that resources should not be widely dispersed, but instead concentrated in the hands of very few. Alternative agriculturalists support

decentralization. Rather than having international or national procedures of food processing, they endorse local or regional methods. They encourage smaller farms, with more farmers, and a wider dispersion of land and other resources.

The second element concerns dependence. To those with a conventional perspective, agriculture should be a large-scale endeavor which involves plenty of capital. They support technological innovations through the use of high-tech machinery, irrigation systems, and agricultural chemicals. Reliance upon external sources of energy, credit, and inputs (such as seeds, pesticides, and fertilizers) is also endorsed. Finally, they seek the advice of scientists, agricultural economists, extension agents at land-grant universities, and other outside agricultural specialists.

In contrast, alternative agriculturalists encourage small-scale production that is not capital-intensive and limits the use of technology. External sources of energy and inputs should be minimized, from this perspective. In accordance with their emphasis on self-reliance, proponents of alternative agriculture support independence from banks and other for-profit lending agencies. Finally, instead of seeking assistance from outsiders, a primary emphasis is placed upon personal knowledge, skills, and local wisdom.

The last element I discuss is what Beus and Dunlap call the tension between “competition” and “community.” Whereas conventionalists endorse practices that support self-interest, alternative agriculturalists see farming as a cooperative endeavor. Conventionalists see agriculture as a business. They hold a rationalistic perspective, supporting speed, large quantities, and high profits. In

accordance with this emphasis on efficiency, they endorse standardized production systems, and the replacement of human labor with technology. A focus on quantity corresponds with the production of highly processed and nutrient-fortified food. Ultimately, short-term benefits such as profits are emphasized over the long-term consequences of farming.

Rather than focus on the business aspects of farming, alternative agriculturalists spotlight its potentially cooperative features. They prefer to see farming as a way of life *as well as* a business. They emphasize quality over quantity, favoring the production of minimally processed, natural, whole and nutritious food. Congruently, they support production systems that are adapted to the local environment. Rather than wishing to minimize the human element in farm work, they consider such labor rewarding and meaningful. They endorse permanence over speed. Therefore, in this perspective, short-term and long-term outcomes of farming practices are equally considered.

There are many agricultural practices and designations that have been subsumed under the umbrella of “alternative.” These include: sustainable agriculture, regenerative agriculture, permaculture, bio-dynamics, agroecology, natural farming, and low-input agriculture (Buttel et al. 1986). Sustainable agriculture refers to farming methods that attempt to “provide long-term sustained yields through the use of ecologically sound management technologies” (Altieri 1995, 89). Ideally, such practices promote ecological stability and sustainability. I focus on organic farming, which is a version of sustainable agriculture that avoids the use of artificial fertilizers and pesticides (Michelsen 2001).

Guthman (1998) provides an insightful social history of organic farming in America. Like hospice, organic farming began as a counter-cultural movement. Instead of resistance to the increasingly rationalized care of the dying, this movement was a response to agricultural industrialization. The focus was on self-sufficiency and a connection with nature, with a commitment to healthful, nutrient-rich food. Over time, organic farming grew beyond communes to include farmers producing food for sale to others. But like hospice, with its initial focus on volunteer caregivers working in small, cooperative environments, organic farming in its purest form involved small-scale farmers practicing at the local level. Guthman (1998) argues that the organic movement raised issues such as: “the mass production of food, the healthiness and safety of food,...the survival of family farms,...the energy costs of food delivery systems, the equity of food distribution, and the community basis of food delivery” (145). And Buck et al. (1997) found in their study of organic farming in California, that organic growers are more concerned with sustainability and the provision of healthful food than with “the logic of profits” (15). These align nicely with the philosophy of alternative agriculturalists described above.

#### Conventional Constraints

In Chapter 2, I discuss how early in the modern hospice movement, some hospice practitioners became concerned with the growing number of health care providers using the word “hospice” for their services. They then formed the National Hospice Organization, which developed standards that hospices had to follow. Some Organic practitioners (in California) initiated an analogous group in

response to concerns about the use of the term “organically grown.” In 1973, the first private certifying organization of organic products was founded: California Certified Organic Farmers (CCOF). They developed standards concerning the growing practices of certified member farms. Such a label became a source of legitimation for those farmers who became certified. CCOF, though the first, is now one of many certifying agencies in California.

Guthman discusses the slow movement to develop *national* standards for organically grown products. Though the federal Organic Foods Production Act (OFPA) was passed during the elder Bush administration, implementation has been stalled by political struggle between the National Organic Standards Board, created by OFPA to determine national standards, and the United States Department of Agriculture (USDA). Finally, in October 2002, legislation was passed that requires anyone who sells a product as “organic” to be certified by a USDA-accredited certification agency (United States Department of Agriculture 2002). The board developed several sub-labels. “Certified organic” means that a product was grown without pesticides, genetically modified organisms, or artificial fertilizers. Processed foods can carry one of three labels: “100 percent organic” means that all individual ingredients are organic; “organic” means 95% of the ingredients are organic; and “made with organic ingredients” means at least 70% of the ingredients are organic.

It should be evident that the term “organic” as it is now officially defined leaves out much of the original ideals of the organic movement. Indeed, as Guthman argues, the term has been stripped down to a mere description of



acceptable material inputs used in agricultural production. These simplified standards should be attractive to large corporations that are interested in expanding into the organic food market. And since large corporations are affiliated with supermarkets, which in turn satisfy the convenience of consumers, this means that growers on small farms will find it increasingly difficult to compete.

For small growers especially, the process of certification is expensive and time-consuming. Land itself is not considered officially organic until pesticides have been avoided for at least three years. Small growers could choose to forgo the certification process altogether, but this carries at least two major consequences. Without certification, they are now forced to use other terms to define their foods. And no term carries the same familiarity and significance as “organic,” to consumers. Also, they would be limited to selling their goods locally and informally. As Guthman writes, “They are...effectively shut out of state and nationwide distribution channels, as many distributors and retailers will only buy certified products, and several important buyer states will not even allow noncertified products to be marketed as organic” (146).

Growers and handlers on farms which are philosophically opposed to modern agriculture but undergo certification in order to stay competitive in the practice of organic farming, may be constrained in how alternative they can be. The costliness of the certification process encourages borrowing from an external credit source, which is antithetical to the philosophy of alternative agriculture. This indebtedness encourages an emphasis on efficiency, in order to increase

profits. The standardization of production and use of technology in place of human labor that come along with an emphasis on efficiency contribute to a food production system that is similar to the conventional in many ways. Though certified growers can claim the unique designation of “organic,” the prediction is that they will become more similar to conventional agriculturalists than different, despite any alternative agricultural philosophy. Indeed, in an exploratory study of organic farming in California, the “birthplace of organic regulation” (Guthman 1998), Buck et al. (1997) show evidence of the increasing industrialization of organic production.

### **A Summary Statement**

Hospice workers and organic farm practitioners who work in certified/accredited environments, and alternative public school teachers, all attempt to follow philosophies that question the sole reliance on scientific rationality while working within the confines of the conventional. Without ties to the conventional, they would lack the legitimacy and security that such certification and accreditation offer. Once these ties are in place, however, they are constrained in how alternative they can really be.

Instead of being “outsiders-within,” these people are like “insiders-on-the-exterior.” Patricia Hill Collins (1990) uses the former term to describe women domestic workers of color. She argues that though domestic workers are literally working inside the homes of the people for whom they work, they do not fully belong there. They will never be fully accepted as true *insiders*. Their differential race and professional status keep them from fitting in.

Analogously, hospice workers, alternative teachers, and organic farmers work on the margins of their respective conventional arenas. They will never be true *outsiders*. They can say they are different, but still maintain the security and legitimacy that comes with being affiliated with the conventional. They are insiders-on-the-exterior: marginal insiders who rely on conventional affiliation for security and legitimacy. Ultimately, despite their alternative philosophies, they end up offering just another option within the broader conventional system.

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