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Choosing Hospice or Choosing Dying: Patient Autonomy and Home Hospice Care

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy

in

Sociology

by

Ellis C. Dillon

Committee in charge:

Professor John Hyde Evans, Chair
Professor Catherina M. Gere
Professor Isaac William Martin
Professor Steven Martin Parish
Professor Christena L. Turner

2013

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Chair

University of California, San Diego

2013

DEDICATION

I dedicate this dissertation to Rick, who was my biggest supporter throughout this endeavor. Without the love and support of all my family this project would have never been.

This dissertation is also dedicated to the patients, family members, staff and volunteers I met at Pacific Hospice. You opened a window into a very personal and powerful experience that we must all face in our own time. I am especially grateful to the patients and their family members who believed that sharing their stories could lead to an improvement in end of life care for future generations. I hope this dissertation does you justice and provides a path for us to follow toward a better approach to end of life care and dying.

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Chapters 3, 4, and 5 are currently being prepared for submission to journals for publication. The dissertation author was the primary investigator and author of this material.

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ABSTRACT OF THE DISSERTATION

Choosing Hospice or Choosing Dying: Patient Autonomy and Home Hospice Care

by

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Doctor of Philosophy in Sociology

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Professor John Hyde Evans, Chair

Up until now, scholars who studied end of life medical care and patient autonomy have concluded that dying patients have little opportunity or desire for control over medical treatments, contesting that they are constrained by medical authority and institutional features. This dissertation argues that there is a serious flaw in this research and therefore its conclusions. This research conceives of these choices as “medical decisions” and consequently focuses on the interventions of medical professionals and institutions. *The existing literature makes too clean a distinction between medical decisions and social decisions.* In examining the case of home hospice care I find that

many dying patients have both the opportunity and desire to make many significant choices about their medical care at the end of life. Patients generally desire autonomy and when they resist making choices it is not due to deference to medical authority, but instead due to the complex social factors they must weigh in making decisions about medical care. Patients experience an intermingling of social and medical concerns that make it difficult to meaningfully draw a line between medical decisions and social decisions. Although this research involves home hospice care, I suggest that it illuminates social factors common to all medical decision-making, but which are difficult to discern in conventional research in hospital or outpatient settings. I provide five empirical chapters to support this conclusion showing how physicians, patients and their family members, hospice workers, and external institutions all conceptualize hospice care as a social decision.

CHAPTER 1. HOSPICE CARE AND THE SOCIAL NATURE OF MEDICAL DECISION-MAKING

Individualism and personal choice are foundations of American ideology, yet in the realm of medicine these concepts are more ideals than reality. The conflict between individual choice and structural and systematic constraints on choice has been detailed in the health care system, where the principle of patient autonomy is put on a pedestal yet rarely achieved in practice. Current research on medicine suggests a fundamental problem; patient autonomy is enshrined in public discourse and policy, but the structure of medical care limits and thwarts many patient choices. Nowhere is the idea of personal choice more important than in questions of life and death, yet it is in just these life or death situations that sociologists document the most constraints on patient choice (Anspach 1993; Kaufman 2005; Timmermans 1999; Zussman 1992). These studies of end-of-life care often focus on discrete medical treatments regarding issues such as life support, and ignore a multitude of important choices patients make or are denied. This vein of research further cements a problematic notion of choice by focusing on medical choices as a separate from other life decisions and social context.

In this study I examine the case of home hospice care and find that patients have both the opportunity and desire for autonomy, but more importantly they experience medical decisions as interwoven and often inextricable from social decisions. Medical care decisions not only have strong social meanings, they are influenced by social motivations, and lead to social consequences. These social concerns are a powerful

influence that is difficult to observe in institutional settings, such as hospitals or doctor's offices where institutional power is at the forefront.

Yet patients experience the vast bulk of their illness at home, not in hospitals, and the majority of medical decisions they make occur outside of doctor's offices.

Understanding the social context of medical care and the illness experience illuminates how patients who resist or embrace the ideal of patient autonomy may not be responding to professional or institutional factors but instead they may be reacting to their own social circumstances, such as their personal beliefs, family background, and financial situation (Kleinman 1988). I provide five empirical chapters arguing that medical decisions should be understood as social decisions, and how physicians, patients, family members, hospice workers, and external institutions all contribute to the conceptualization of medical care decisions as social decisions.

I show that "medical" decisions in the realm of hospice care are often social decisions, invested with social meaning and social consequences (Conrad 1985). These choices within the realm of home hospice care are invested with enormous emotional weight; they are not simply choices about medical care, but choices about how we wish to die. Through interviews and ethnographic observation of participants in a home hospice program, I examine when, why, how, and what choices are made. I find that medical decisions are social in four ways: they are socially defined, they are influenced by social factors, they in turn influence social life, and they are susceptible to institutional pressures that enable and constrain choice. While hospice care and hospice patients might be dismissed as an atypical case study, I argue that these findings are relevant beyond this population both to decision-making with respect to chronic illness, and to end of life care

in hospitals. While on paper hospice patients seem to be separate and distinct, in practice patients experience a fluidity between categories such as chronic illness and terminal illness, hospice patient, hospital patient, and outpatient, and even living and dying.

In some ways hospice does diverge from other forms of health care. Hospice represents an alternative type of medical care that acknowledges the dense intermingling of medical and social decisions and processes. This interdependence of social and medical perspectives shifts hospice care further down the spectrum away from medicalization and toward demedicalization. The holistic work of hospice care encourages a focus on the illness experience, prioritizes the value of “caring”, both physical and emotional, and fosters patient autonomy. These findings suggest a broader pattern showing how medical institutions can paradoxically have demedicalizing tendencies that foster patient choice. I contend that hospice care provides a counterexample to the sociological concept of growing medicalization and institutional constraints on choice.

Moreover, the emphasis on ethnographic techniques and the perspective of hospice patients allows this research to expose the problems with conventional assessments of patient choice. I find that sometimes a decision that appears to be made by a physician or medical professional is actually made by a patient or family member. Likewise, some patients who appear to be deferring to medical authority are in fact responding to social concerns. Decisions, from whether to begin hospice care to whether to take certain medications are multifaceted and much analysis is social rather than medical in nature. While social scientists will not be surprised to hear that medical

decisions are indeed social, I illustrate how and when social context factors into individual decisions and influences the desire to make decisions itself.

THE INSTITUTIONAL CONTEXT OF MEDICAL DECISIONS

The bulk of research on patient autonomy as it occurs in practice revolves around hospital-based care and focuses on how the medical authority of professionals and institutional power constrains patient choice with respect to medical decisions. This literature tends to focus on patient disempowerment and institutional constraints on patient choice. I critique this body of literature on two grounds. First, it restricts analysis to a small segment of medical decision-making. Second, by focusing on the perspectives of medical professionals and the setting of institutions it de-emphasizes the social context of these decisions.

Common case studies for analysis of medical decisions include end-of-life decisions having to do with life-support technologies such as ventilators, feeding tubes, or resuscitation (Anspach 1993; Lock 2002; Rothman 1991; Timmermans 1999). Also common are analyses of how physicians and patients confer about how to treat serious ailments with multiple treatment trajectories such as cancer (Lutfey and Maynard 1998; Taylor 1988). These studies often show that while physicians profess to give patients choices, in practice they are often approaching patients with their minds already made up about what intervention should be used and then are persuading the patient or family to assent to that plan (Anspach 1993). These studies do not contest that medical decisions are not social, instead in many cases they point out how social factors influence medicine,

via the construction of medical knowledge, health care bureaucracy and systems, and occupational hierarchies. They expose how social factors delineate the strategy and choices of medical professionals, but they rarely illuminate how patients and families respond and make their own set of choices. In this dissertation I show that many decisions that might superficially appear to be about medical questions or health are primarily seen as social, psychological, spiritual, administrative, or even financial.

This research on medical decision-making tends to center upon a small and select group of interventions, ignoring the wider scope of medical decisions patients face. Much of the research on medical decision-making relates to the field of medical ethics or bioethics and often glosses over what decisions are or should be considered under this umbrella (Zussman 1997). How can we define “medical decisions”? Much research on medical decisions presupposes that decisions are medical in nature because they either (1) relate to medical interventions, or (2) are under the power or authority of medical professionals. In other words, if a physician makes a decision, or if that decision involves the use of medical interventions it is seen as a medical decision. In much research the category of “medical decisions” is never defined, but revealed through practice and exploration of issues such as bioethics. However, these discussions typically exclude a great number of decisions, from the mundane to the momentous that patients and families generally make by themselves.

Analyses of patient autonomy as experienced in hospitals and outpatient clinics often address a discrete and limited set of medical care decisions. There are many medical decisions made by patients at home and rarely analyzed by social scientists, e.g. Conrad’s study of patients’ decisions about taking epilepsy medication and Zola’s classic

study of when and why patients decide to seek doctor's appointments (Conrad 1985; Zola 1973). Some might argue that the decisions patients make at home are less significant than those made in hospitals. Yet on one level we are accustomed as scholars of public health to understand the myriad ways in which a person's social context, such as socioeconomic status, influences health outcomes via pathways such as education, income, social networks, cultural influences on diet and exercise, community features, social inequality, marital status, and race and ethnicity (Christakis and Fowler 2007; Marmot, Stansfeld, Patel, North, Head, White, Brunner, Feeney, and Smith 1991; Phelan, Link, Roux, Kawachi, and Levin 2004; Robert 1999; Schnittker and McLeod 2005; Wilkinson 1996; Williams and Collins 1995). It is clear that home environment has a large effect on health outcomes. It should be equally true that home environment has a large effect on medical decisions.

As my study reveals a large number of decisions relevant to patient health occur in the home: whether to take prescribed medications, whether to schedule a doctor's appointment, whether to use medical devices, whether to follow a prescribed diet or exercise regimen, whether to move to a nursing home, etc. While these may not fall under the conventional objects of study for medical decision-making, they are perhaps as influential or more influential as any decisions made in doctors' offices or hospitals. Someone who fails to take a critical medication may very well have a health crisis and end up in the emergency room or ICU. Someone who decides not to use a walker or wheelchair may be more likely to fall and again end up in the hospital. These are both medical decisions, and social decisions with health consequences. While we do not think of these as "life or death" decisions, an amalgamation of these decisions not only

influences what health problems people face and perhaps when they die, but it influences their well being and quality of life while living.

By focusing on the perspectives of medical professionals and the setting of institutions much of the literature on patient autonomy de-emphasizes the social context of these decisions. This perspective on medical decisions often privileges the point of view of doctors and other medical professionals, for obvious reasons, they embody expertise and authority with respect to clinical decisions. These studies often portray patients who defer to the doctor's expertise and authority on questions of medical interventions. In many of these case studies of hospitals and ICUs patients voices are notably absent and for valid reasons, as Seymour notes, intensive care medicine is, “conducted around a ‘patient’ who, by virtue of the severity of his or her condition, cannot interact in the everyday, taken for granted sense of the word” (2001, 4). Yet patients and family members consider factors in decision-making that medical professionals often do not. In Kaufman’s analysis of ICU care she describes the case of Mrs. B whose family faced a decision about whether to approve the use of a feeding tube.

In retrospect, the family spoke about how good they thought their mother's hospital care was. But in the end, they remarked, they were alone in making decisions because the medical staff had one perspective--to save life--and they had another--to consider their mother's existential condition. They decided that under no circumstances would they authorize a stomach tube for Mrs. B regardless of the pressure they perceived and in fact, they wanted to remove the nasogastric tube and not replace it with anything. (Kaufman 2000, 11)

Because of the constraints of the hospital setting and perhaps due to issues about access and ethics it is rare to see this perspective on patient and family decision-making. Even research that illuminates the myriad social factors that shape the professional

strategies of physicians and nurses often gloss over the impact of social concerns on patients and family choices (Anspach 1993; Glaser and Strauss 1965; Sudnow 1967; Zussman 1992). In many cases these studies treat patients as the objects of decisions, not pivotal actors in making decisions.

As I show in the next section when patients and families are examined as the primary research subjects a more nuanced picture of social context emerges, one that demonstrates the broad range of issues they consider in conjunction with medical care (Charmaz 1991; Kellehear 1990; Lawton 2000). The intermingling of social and medical decisions is even more pronounced in studies that examine patients (or people with current or future health problems) outside of hospitals and doctors' offices (Charmaz 1991; Klinenberg 2001).

The bulk of contemporary research on end of life care and patient decision-making occurs in hospital settings or outpatient clinics. The nature of institutional settings is often disempowering and constraining, as Goffman portrays in his analysis of "total institutions" (1961). Looking at the experience of hospitalized patients focuses on the time when they are most vulnerable, powerless, and least able to communicate effectively. By focusing on what decisions are made once patients arrive in hospitals we are focusing on the very arena in which patients have the least power and maneuverability. Hospitalized patients are often bedbound in an unfamiliar environment, emotionally and physically suffering, they are often unable to communicate effectively, and are always disempowered. We are looking at the setting in which they are "patients"—not people with illnesses. While contemporary hospitals are perhaps not as extreme a "total institution" as mental asylums were in the 1960s they are still as close as

most people come to being taken from everything familiar and immersed in a controlling and unfamiliar institution (Goffman 1961).

Institutions, especially hospitals have been shown to constrain patient autonomy in a variety of ways. For patients and family members in high stress ICU situations, research portrays the impossibility of full patient autonomy. Scholars show that the “decisions” patients are presented with are highly scripted and presented in such a way that patients are guided to choose whatever the medical professionals recommend (Anspach 1993; Zussman 1992). Institutional attempts to further patient autonomy appear to fall flat; indeed, devices intended to further patient autonomy in decision-making, such as informed consent forms are often not explained to patients, and patients sign them by rote instead of after careful consideration (Akkad, Jackson, Kenyon, Dixon-Woods, Taub, and Habiba 2004; Corrigan 2003; Zussman 1997). Serious efforts to improve patient autonomy through clinical intervention in the use of Advance Directives, such as the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), failed to achieve any improvement (SUPPORT Principal Investigators 1995; Teno, Lynn, Wenger, Phillips, Murphy, Connors Jr, Desbiens, Fulkerson, Bellamy, and Knaus 1997).

In much of this research patient and family narratives are nonexistent or secondary to the perspective of medical professionals. The institutionally entrenched power of the medical professionals and especially physicians also seems to be at its peak in hospital care. In one example Anspach shows how the Neonatal Intensive Care Unit (NICU) uses a collective decision-making process, in which doctors and nurses confer about possible treatments, but parents are outsiders in this process (1993). Doctors and

nurses may disagree on an infant's prognosis and treatment plans, but eventually they reach a consensus and only then do they present their plan to parents for approval.

Anspach likens this tactic to asking for "informed assent" as opposed to true "informed consent" in which parents are presented with a range of options and their potential consequences. Anspach suggests that in the case of the NICU, true informed consent may be impossible to attain: "Given the persuasive practices that I have just described - framing the medical "facts" of the case, appealing to medical technology and expert authority, and formulating unequivocal moral precepts - it is hardly surprising that very few parents challenge physicians' interpretations or reject their recommendations" (1993, 98). Although the medical community gives official recognition to the value of patient autonomy (Beauchamp and Childress 2009), the structure of the institution, and the vast differences in expertise, knowledge, and authority, all stack the odds against the patient (or parent) and in favor of the physician. Even studies of interactions in doctors' offices and outpatient clinics contain this bias toward finding extreme institutional power.

By focusing on these medical settings we are overlooking the arena in which patients have the most power and which ultimately has the greatest influence on their overall health and well being: home. By "home" I refer to what happens when patients leave doctors' offices and are discharged from hospitals. While a hospitalization may occur at the end of an illness, there may be days, weeks, months or years at home before that final hospitalization and death, and for an increasing number of people death itself may happen at home with hospice care. Indeed a new type of tool, a Do-Not-Hospitalize (DNH) order, is increasingly used for patients with dementia to avoid hospitals and bypass some of the issues that arise surrounding life support in ICUs (Mitchell, Teno,

Intrator, Feng, and Mor 2007). This time at home is an important part of the illness experience and influences both medical choices and the possibility of future hospitalizations.

The literature on the institutional context of medical decisions largely focuses on the lack of autonomy patients experience within the confines of medical settings. While attempts are made to ascertain what the patients and family members' perspectives are on their care, the bulk of research focuses on the narratives and observations of the medical professionals. Sociologists have learned much about the social forces influencing medical professionals from classic studies of "detached concern" (Lief and Fox 1963) and professional dominance (Friedson 1970), to more recent analysis of the pressures and professional strictures upon physicians (Kitchener, Caronna, and Shortell 2005). Simultaneously a growing interest in the power dynamics of the physician-patient relationship has sparked research on how physicians and patients communicate and make referrals or other treatment decisions (Broom, Kirby, Good, Wootton, and Adams 2013; Lutfey and Maynard 1998; Ong, de Haes, Hoos, and Lammes 1995; Taylor 1988). This vein of research is critical to understanding how to influence patient autonomy for better or worse, yet it too often is researched from the point of view of physicians and is often addressed as a problem for them to manage within their profession (Billings J 2011; Quill and Brody 1996; Whitney and McCullough 2007). What is lacking is an effective way to integrate the experience of patients and family members into this research agenda on medical decision-making and patient autonomy. A large body of research on the social context of medical care and illness offers a path to follow toward research methods that will expose the social context of patient and family decisions.

THE SOCIAL CONTEXT OF MEDICAL DECISIONS

The sociological literature on the social construction of medical knowledge, the social meaning of medicine, the illness experience, the physician-patient relationship, and the social determinants of patient preferences all provide insight into the social concerns that would be relevant to questions of patient choice. These diverse scholarly topics all stress the social influence of individuals and institutions upon medical topics ranging from how diseases are conceptualized, to how patients interact with physicians. I provide an overview of this literature arguing that it fails to provide a conceptualization of how patient autonomy and social context combine in practice.

There already exists a vein of sociological research that questions our assumptions about what constitutes a “medical” decision, and indeed what constitutes sickness and health more broadly. Part of this intellectual endeavor examines how medical knowledge about disease and treatment is socially constructed in response to professional, institutional, or social movement/activist efforts (Epstein 1996; Loe 2004; Wright and Treacher 1982). Durkheim himself delved into an exploration of the social construction of sickness and health as categories which are more social than biological/physiological (1982, 86), and his classic study of suicide revealed how epidemiological patterns could be culturally determined (1951).

In a classic article Zola questions the very labels of sickness and health and how they are related to health care services (1973). He notes that many “sick” people do not go to the doctor, or delay going to a doctor, and are not officially recorded in our

statistics on morbidity. Writing about pathways to the doctor Zola suggests that people seek medical care and become “patients” not because of any change in their health, but because of changes in their social-psychological circumstances (1973). In his examples gleaned from talking to patients in the waiting room of an outpatient clinic (before they had officially become “patients”), he discovers that patients did not schedule doctor appointments because they became suddenly ill or because their illness became worse. Instead they scheduled doctor’s appointments in response to changing social situations or pressures. In this way social factors are the driving factor behind a “medical” decision – whether or not to see a doctor.

Just as Zola and others deconstruct “health” and “sickness” as social constructions (Durkheim 1982; Zola 1973), I deconstruct “medical decisions” as a category. While patients seeking a doctor’s appointment are assumed to be making a medical decision, so are the many patients who decide not to see a doctor for a problem and are not captured in our conventional research populations. Zola points to a great interdependence between life decisions and medical decisions. My study finds an even greater intermingling of medical and social decisions in the realm of home hospice care. Indeed the medical decisions of home hospice patients have both social motivations and social consequences.

A burgeoning endeavor within medical sociology emphasizes the value of “patient-centered” analysis and analyzing “illness experience” through the medium of “illness narratives” (Bury 1982; Conrad 1985; Frank 1991; Frank 1995; Kleinman 1988; Mattingly 1998). In contrast with the aforementioned studies of medical decision-making these studies tend to be based on interviews with patients or even auto-ethnographies (Bochner 2000; Frank 1995; Parish 2008; Rier 2000). These studies explore the impact of

illness on social life and vice versa noting that illness has as astounding impact on all aspects of social life and has moral and existential elements (Charmaz 1991; Frank 1991; Kellehear 1990; Mattingly 1998). Frank eloquently expresses this revelation, which he himself experienced firsthand, saying, “What happens when my body breaks down happens not just to that body but also to my life, which is lived in that body” (1991, 8). This research chronicles the profound social meaning and social ramifications of illness.

The social meaning of particular forms of medical care, in my case hospice, can influence how patients use medical care. Taking a “patient-centered” approach to understanding what doctor-centered analyses call “non-compliance” (when patients do not take medications as prescribed), Conrad emphasizes that, “Most people with illnesses, even chronic illnesses such as epilepsy, spend only a tiny fraction of their lives in the ‘patient role’” (1985, 31). He finds that the desire for control leads some epileptic patients to “self-regulate” their medication usage in order to mitigate “social side effects,” to test the medications efficacy, to control dependence, to de-stigmatize their condition, or as a “practical practice” (e.g. stopping medications when drinking alcohol or increasing medications when in stressful situations). As I will show the social meaning of hospice care also strongly influences when and how patients use hospice care.

It is telling that Conrad’s research was based on interviews with patients with epilepsy in their homes not at doctors’ offices (1985). People with illnesses do not suddenly become “patients” and leave the rest of their responsibilities and lives behind. They have jobs, family obligations, housekeeping tasks, and other responsibilities, hobbies, and daily activities. Focusing on the home setting also reveals the many ways in which dying is not an individual experience, but instead a social experience an entire

family undergoes. If we understand illness as the social manifestation of disease, then family members are likewise facing illness. As Arthur Frank laments, “Medicine assumes that the person who has the disease is the only one who is ill” (1991, 105). The social experience of dying presents another challenge to cultural ideas of individualism and the principle of patient autonomy.

Past research on patients often either (1) lumps the patient and family members together under the umbrella term “patient” or (2) analyzes patients in isolation, decontextualized from their families. Collapsing patients and family members together into one category poses a problem because family members' experiences and motivations are rarely perfectly aligned with that of the official patient (Carr 2003; Casper 1998). For example, Deborah Carr's fascinating study examines longitudinal survey data and finds that the definition of a “good death” may vary by role. She finds that the dying individual prefers a death that is sudden and not in a nursing home, meanwhile the spouse prefers to have time to prepare for the death and say good-bye, and a nursing home or other professional care helps relieve the care-giving burden on the spouse (2003). Consequently it may sometimes be true that treatments that benefit the patients may adversely affect family members, and vice versa.

The second problem with the category of “patient” is found in research that does not analyze the patient as a part of a family unit. It is often the case that at some point during the dying process patients must rely on others to speak for them and act as surrogate decision-makers, especially with the advent since the 1970s of technologies such as ventilators and tube feeding. Family members are therefore important actors who shape the medical treatments and experiences of the “patient” (Carlander, Ternstedt,

Sahlberg-Blom, Hellström, and Sandberg 2011; Charmaz 1991; Lock 2002). Margaret Lock shows how family members take on a decisive role in the case of “brain death” in both Japan and the United States (2002). In both countries it is the patient's family who has the final say in when the patient should be “unplugged” and whether organs can be used for transplantation. Although brain death is an extreme example, in all cases in which patients are temporarily incapacitated, unconscious, children, cognitively disabled, or have Alzheimer's/dementia, family members guide treatment. Even in cases in which the patient has “decisional capacity,” it is frequently the case that patients choose to rely on their family members to either help them make decisions, or even to make decisions for them.

In the above review of the literature on the social context of illness I show that a strong trend within sociology is toward examining the ramifications of illness on social life and the impact of social life on illness. I contend an examination the social context of illness must include both patients and family members as critical actors, and the ideal setting is the family home.

WHY STUDY HOMES HOSPICE CARE?

This study looks to home hospice care in order to study the intricacies of patient autonomy. There are two powerful reasons to study home hospice care. First, hospice care specifically and end-of-life medical care more broadly are large and growing segments of medical care. In 2011 44.6% of Americans who died that year were receiving hospice care at the time of their death (National Hospice and Palliative Care

Organization 2012). In Chapter 2 I detail the history and growth of the hospice movement, here I simply note that most Americans will at some point during their lives face a choice about whether to use hospice care either for themselves or for a loved one. The findings of this study and the narratives of the hospice patients, families, and workers, can both educate academics about the nature of patient autonomy and educate the public about what the hospice experience is like from the insider's perspective. The second reason hospice care is the ideal object of study is that it provides insight into several dimensions of patient autonomy. Hospice care is the ideal subject because: (1) it is conceptualized as a “choice,” (2) hospice care provides institutional care at home, (3) it involves a range of social and medical decisions, (4) hospice provides care to patients and their family members, and (5) it concerns a critically important social and medical event – dying. I detail the reasons that each of these traits is critical below.

Hospice care is conceptualized as a “choice”

Hospice care is an ideal object of study because it was explicitly conceived as a “choice” for dying patients, an alternative to more aggressive care. Patients can continue with mainstream medical care¹ or they can choose hospice care. Patients may end up in an ICU for reasons outside of their control, for example due to the exigencies of an

¹ In this dissertation I refer to “mainstream medical care” as a convenient foil for hospice care. By mainstream medical care I refer to hospital and outpatient clinic based care for terminal illnesses. I dub this mainstream care because this is the default care patients receive and most public discourse and media representations of dying focus on this type of care. In contrast the hospice movement conceptualized itself as an alternative to and in some ways a rebuttal of this more conventional care.

emergency situation. Patients are not admitted to hospice unexpectedly or on an emergency basis, it is a deliberate decision.

However, hospice care is not a choice that patients or their families make in isolation. They must work in conjunction with medical professionals and institutions to opt in to hospice care. In 1982 when regulators realized how efficient and cost-effective hospice care was for dying patients they passed a bill providing Medicare funding for hospice (Siebold 1992; United States Congress 1982). There was a caveat: hospice patients had to be given an official medical prognosis of six months or less to live and they had to end all curative medical care. The admission of impending death and the act of relinquishing possible cures came to define the meaning of hospice for many Americans. Thus, while the hospice social movement has become institutionalized and bureaucratized as a major part of our health care system, it remains separate and stigmatized (Siebold 1992). The choice to begin hospice care is also shepherded by physicians who have their own biases about hospice care and must act as gatekeepers providing (or failing to provide) referrals (Bradley, Fried, Kasl, Cicchetti, Johnson-Hurzeler, and Horwitz 2000; Brickner, Scannell, Marquet, Ackerson, Brickner, Scannell, Marquet, and Ackerson 2004), and thereby limiting the role of the patient in this “choice”. Therefore hospice involves a range of choices involving patients, families, medical professionals, and institutions. This study reveals the complexity and contradictions in this conceptualization of hospice as a choice.

Hospice at home – outside of the total institution, inside a new institution

Home hospice care provides a unique window into patient autonomy because it occurs outside the strongholds of medical facilities and in the patient's domain: the home. However, hospice care decisions are not decoupled from institutional medicine, they simply represent a new type of institutional care which operates within family homes. Examining medical decisions made at home is increasingly important as most of people's experience of dying and indeed of chronic illness occurs at home, interspersed by doctors' appointments or hospitalizations. Yet, hospice is itself a form of institutional medical care, providing a useful comparison to other types of institutions.

There are three reasons research on patient autonomy must consider what happens outside of medical facilities and in patients' homes. First, the bulk of a person's illness is experienced at home. Therefore in order to understand the illness experience, we must examine not only what happens in doctors' offices and hospitals, but in family living rooms. Second, many medical decisions occur at home. Scheduling doctor's appointments, taking medications, following (or not following) a diet, are all decisions that occur within the family home. Third, medical institutions and professionals are increasingly entering the home. Home hospice care is the most obvious examples of medical care provided in homes, but the home health industry, and the mingling of home and medical care in the case of nursing homes, assisted living facilities, and other residential care facilities are other examples.

Other sociologists studying hospice largely ignore the role of the home setting in influencing hospice care. There are good reasons for this oversight, in the United Kingdom and Australia where much research on hospice has been conducted the majority

of hospice care occurs in inpatient facilities (Broom and Cavenagh 2011; James 1992; Lawton 2000; McNamara 2004). In the United States home hospice care is the norm, yet even research on home hospice patients often does not dwell on how care at home is distinctive than other forms of institutional care (Fox 2010). Indeed even in the United States “hospice” is often associated with an institutional setting and the general public is unaware that most hospice care occurs at home (Kreling, Selsky, Perret-Gentil, Huerta, and Mandelblatt 2010, 432). Many critiques of hospice care as an example of a social movement which has become institutionalized, secularized, or bureaucratized come from examinations of countries and hospice systems where inpatient hospice care is the norm (Bradshaw 1996; James and Field 1992; McNamara, Waddell, and Colvin 1994). While hospice services are provided in patients’ homes, hospice care is itself an institution, with an ideology, policies, and bureaucracy. Looking at hospice care has the further advantage of offering a comparison to other institutions.

Expanding the definition of “medical” decisions

In the realm of home hospice care the category of medical decisions is expanded on two fronts: medical decisions are more transparently intermingled with social decisions, and a wider variety of medical decisions are available to observe. Home hospice care offers the opportunity to observe a type and breadth of decision-making that is impossible to glimpse in hospitals or outpatient clinics. When and if patients schedule appointments, how they interact with hospice workers, when and why they ask for help, these are all subject to patient choice as well as many constraints on choice. Many

choices are both medical decisions and social decisions, whether to use a walker, sleep in a hospital bed, or move to a nursing home are good examples. Social pressures often influence medical decisions such as whether to start hospice, take medications, or use medical devices. In this study I look at many choices that do not fit the conventional or most obvious definition of medical decisions. In doing this, I offer a new approach to studying medical decisions.

Under the aegis of medical care hospice workers encourage patients and family members to make choices that run the gamut from those which seem strictly medical, such as whether to increase a morphine dose, to those that seem strictly social, such as when and how to make funeral arrangements. The patients in this study address two types of decisions on a regular basis; decisions about caring and decisions about preparing for dying. Decisions about care run the gamut from what hospice services to utilize, to what treatments, medications, or medical devices to use, to what kind of relationship to have with hospice workers. Decisions about preparing for dying may include what mortuary/funeral preparations to make, when and how to say good-byes to friends and family and seek closure, and most perplexing how to face impending death.

While this study focuses on hospice care and dying patients I contend that these findings about medical decision-making can be generalized to other groups of patients, most obviously those living with chronic illness. All patients with chronic illnesses and some with more transient ailments have social motivations for their medical decisions, and face social consequences for the same decisions. This study reveals how a patient's social context profoundly influences their decisions about care, a process that is often obfuscated or overlooked in research occurring in medical facilities.

Hospice is for patients and families

Home hospice care provides a window into how patients and family members independently and collectively deal with illness (Carlander et al. 2011). Analyzing the role of family members is critical for two reasons. First, family members often influence patient choice or sometimes act in the stead of a patient. Second, family members are experiencing the process of dying alongside the patient but from a difference angle. Hospice care offers a unique opportunity to study patients and family members in conjunction, and to compare patients with family to those who are alone. While many studies of patients at the end of life either overlook or are denied access to family members, home hospice care offers a unique angle from which to study the role of family members in decision-making and in the wider experience of dying. Because hospice care explicitly treats both patients and family members as its clients, and because family members are often living in the home with patients (or visiting every day) I was able to enroll many family members in this study. This study finds that family situation and family member preferences are some of the most powerful forces shaping patient choice.

Hospice is for dying: life and death decisions

Perhaps most importantly, hospice care is a case study for analyzing decisions that are of paramount importance - decisions related to death and dying. Hospice patients can offer insight into the vast spectrum of choices patient with terminal illness face. Many hospice patients have experienced the entire range of options open to dying

patients (including ICU care and resuscitation). Since they are at the end of a (typically) long illness they can reflect on all the choices they faced during their illness experience. While many hospitalized patients are unable to communicate or in circumstances that are not conducive to open communication, the hospice patients enrolled in this study were still at a phase of their illness when they could freely communicate. Since these patients were able to provide illness narratives about their medical care prior to hospice, their transition to hospice, and their hospice care, they provide a more panoramic view of the scope of choices patients make or are denied during their illness.

Many studies of end of life care only focus on very specific interventions that occur near death, such as treatment decisions about intubation, tube feeding, or CPR, made in Intensive Care Units (ICUs) (Anspach 1993; Timmermans 1999; Zussman 1992). These and other studies that more explicitly focus on patient autonomy often find that hospital institutional constraints determine patient experiences and often guide treatment decisions (Kaufman 2005; Seymour 2001). While this research is able to teach us important lessons about related topics such as professional expertise, authority, and institutional power, they address a specific sub-category of decisions, often about “life support.” Life support decisions have long been the focus of ethicists and social scientists (Rothman 1991; Sudnow 1967; Timmermans 1998). However, decisions about resuscitation, intubation, tube-feeding, and withdrawing care are preceded by a broad

array of choices that determine whether someone ends up in the ICU². These studies look at the final decisions in a long chain of events.

Many end of life decisions, although not about “life support”, are nevertheless critical and can indeed dramatically change health outcomes. It is equally true that many decisions made in hospitals, while at face value are seen as “life and death” decisions, are not as decisive as suggested. Zussman’s data on patient survival following admission to two hospital ICUs suggests that even those who live to leave the ICU do not necessarily live to leave the hospital, and that they often die soon after they are discharged (1992, 23). Kaufman’s study of ICUs suggests that they often house chronically ill patients who are repeatedly re-hospitalized, the “revolving door pathway”, or patients experiencing the “heroic intervention pathway”, in which they are near death but all attempts are still made to “save” their life (2005). In both cases there are few patients who “recover”, in the sense of returning to their pre-illness life, after a hospitalization. Some of the interventions hotly debated as “life or death” decisions, such as resuscitation, have remarkably low success rates. As Timmermans points out, even when resuscitation is successful the resuscitated individuals do not become healthy, they typically still have the underlying conditions (e.g. heart disease) that caused their hearts to stop beating in the first place (1999).

For most patients “life and death” decisions are more about whether to try to delay death rather than “save life”, with some researchers explicitly addressing the question of whether these interventions prolong life or prolong death (Amella, Lawrence,

² While I do not suggest that patients have complete control over whether they end up in an ICU, neither are they powerless. Patients often have agency in the sequence of events that led them to the ICU.

and Gresle 2005; Rothman 1991). Consequently a rich body of research attempts to glean what types of patients prefer the most aggressive treatments and what types of patients prefer to limit aggressive treatment and opt for hospice, palliative care, or even euthanasia or physician-assisted suicide (Benson 1999; Burdette, Hill, and Moulton 2005; Emanuel, Fairclough, Daniels, and Clarridge 1996; Steinhauser, Christakis, Clipp, McNeilly, McIntyre, and Tulsky 2000; Wasserman, Clair, and Ritchey 2005). Yet this question of patient preferences presupposes that patients have strong preferences and desire to make decisions, an assertion that is often contested (Drought and Koenig 2002).

Some research suggests that the very principle of patient autonomy is problematic and patients do not want to take control or are inconsistent in their preferences (Ditto, Smucker, Danks, Jacobson, Houts, Fagerlin, Coppola, and Gready 2003; Salmon and Hall). Although patient autonomy is an enshrined principle of bioethics (Beauchamp and Childress 1979; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979), studies of physician-patient interaction and communication often conclude that there should be varying levels of physician power and patient autonomy in different situations (Emanuel and Emanuel 1992; Quill and Brody 1996). Some scholars go as far as to suggest that autonomy is a faulty ideal (Drought and Koenig 2002; Mol 2008). Drought and Koenig elaborated upon the limitations of the “autonomy paradigm” and other obstacles to its success (2002). In a more radical example, Mol suggests that the well being of patients with diabetes is improved by prioritizing patient *care* over patient *choice* (2008).

It remains unclear if, when, and how patients desire autonomy. Some demographic characteristics may predict attitudes toward decision-making. As Gott et al.

suggest older patients may have a more trusting and deferential attitude toward medical authority and family influence: “there is evidence that some older people share the ‘other culture’ perspective, placing greater trust in authority (and within this context medical authority) and allowing (and in many instances preferring) family members to make decisions for them” (2008). Other groups, particularly African-Americans, have been shown to distrust medical authorities making decisions for them and are most apt to push for all available treatments. The cultural history of African-Americans as exploited both inside and outside the arena of health care, as well as the religious-spiritual beliefs of many African-Americans, appear to play a role in this group difference (Crawley, Payne, Bolden, Payne, Washington, and Williams 2000; Gamble 1997; Johnson, Kuchibhatla, and Tulskey 2008).

Studying a population that is dying is instrumental because the decisions they make are of critical importance. Hospice care patients and family members are aware that their medical decisions have both a profound meaning and important consequences. Hospice care is another venue for observing many of the debates about life and death, and is a venue in which patients have a more powerful voice. It is the social meaning of hospice care, as symbolized by the idea of “giving up”, that frames many decisions about hospice care. Studying hospice patients provides the added advantage of including patients who typically know they are dying, since hospice care eligibility requirements mandate a physician give the patient a prognosis of six months or less to live³.

³ In Chapter 3 I discuss some of the intricacies of prognosis. Many hospice patients are never explicitly given a prognosis, nevertheless more than any other group hospice patients are aware of their impending mortality.

To summarize, there are five reasons home hospice care is the best choice for studying the manifestations of patient autonomy. (1) Hospice is itself conceptualized as a choice. (2) Hospice is a form of medical care that occurs at home but it still within the framework of an institution. (3) Hospice exposes a new set of medical decisions to the sociological gaze, and problematizes how we distinguish between social and medical decisions. (4) Hospice addresses patients and family members in conjunction, exposing the ways family members shape patient choice and the ways in which dying is a social experience. (5) Hospice care concerns life and death decisions with great social meaning. I conclude that studying home hospice care offers the ideal peephole into the types of choices and constraints on choice that patients face.

RESEARCH QUESTION

This inquiry into the role of autonomy in hospice care was guided by a series of related questions.

1. How do patients transition to hospice care? Do they “choose” hospice or is it “chosen” for them?
2. What choices do hospice care patients and their family members face during their time receiving hospice care?
3. Do patients want choice? If so which choices do they want? Which choices do they resist?
4. Are choices perceived as “medical” decisions or as “social” decisions?
5. What social factors influence patient autonomy and choice?

6. How do social decisions influence medical care?
7. What institutional forces shape patient autonomy, either restricting or enabling autonomy?

The answers to these questions are not only of great clinical importance, in that they allow us to envision how to improve patient experiences at the end of life, but they are of theoretical value. The answers further our understanding of the role of patient autonomy in medical care, and the nature of individual autonomy in social life.

METHODOLOGY AND PARTICIPANTS

To answer questions about the choice or lack of it that patients and families experience during the dying process requires in depth qualitative research, specifically ethnography combined with interviews. Interviews enable participants to share thoughts and memories, and observation allows the researcher to glimpse aspects of experience that remain unspoken. With reference to exploring choice, or lack of choice, descriptions of certain types of choices are accessible in interviews: for example, patients and family members can recount who made the decision to start hospice care and why. Other choices may be invisible to patients or patients may be physically or emotionally unable discuss them. The inclusion of interviews with family members, caregivers, and hospice workers allowed me to glimpse both a wider range of choices, and to see how choices were influenced by a variety of actors.

I outlined above why hospice care is the ideal object of study in an inquiry into decision-making at the end of life and patient autonomy, but why specifically focus on *home* hospice care? First, the vast majority of hospice care in the United States occurs at home (either within family homes or in other “homes” such as nursing homes). In 2011 the National Hospice and Palliative Care Organization (NHPCO) estimates that 41.6% of Americans who died that year died in their family home (National Hospice and Palliative Care Organization 2012). While other countries such as Britain have a strong history of inpatient facility-based hospice care, in the United States care at home is the norm. More importantly from an ethnographic perspective, doing interviews and observation visits in patients' homes is a way of shifting the lens from exclusively medical care, to a wider view including home and personal life. People’s lives center on their homes and their families, and this perspective is often sorely lacking in research that catches patients during the brief windows of time in which they are in medical facilities.

Likewise, to try to capture a more holistic view of dying and decision-making, it was important that patients not be the only focus of this investigation. Family members, paid and unpaid caregivers, and hospice workers (including nurses, social workers, spiritual counselors, home health aides, and volunteers) were all included as participants in both interviews and observation. It was especially important to include family members who are often instrumental in making decisions and in changing the experience of dying. Hospice workers likewise are important in both their influence on patients and family members and their symbolic importance as representatives of the institution and reminders about the meaning of hospice.

This research focuses on the experiences of participants at a large hospice in the Southwest, which I will give the pseudonym Pacific Hospice. Pacific Hospice is representative of some of the trends in hospice care. It is a large non-profit organization serving a large and diverse population in a metropolitan area that includes urban and suburban areas. As an organization this hospice reflects some of the evolutions and tensions within hospice care since its inception in the 1970s in the United States. Pacific Hospice was founded at the beginning of the hospice movement and reflected the ideals and philosophy of leaders such as Cicely Saunders. However, in recent years this hospice has expanded its connections with the broader field of medicine. Pacific Hospice initiated and expanded its own research program, and it forged connections with a medical school that now has all medical students do a rotation with this hospice.

I became familiar with this hospice as a home care volunteer in 2007-2009. As a home care volunteer I went through the hospice's extensive volunteer training outlining their philosophy and practices, and then spent time visiting patients in their homes providing companionship, social interaction, and respite for caregivers. This experience as a hospice volunteer piqued my interest in how patients and family members made choices about dying, and led me to seek the support of the hospice in conducting my dissertation research. Once the research received IRB approval from both UCSD and Pacific Hospice, the hospice assisted me by recruiting patients to enroll as the first subjects in the study. A hospice employee contacted all patients meeting the inclusion criteria: patients had to be enrolled in hospice for at least two weeks, they had to be adults, English speakers, be able to sustain wakefulness for at least a hour, be able to communicate verbally, and be able to give informed consent. A hospice employee gave

screened patients a brief description of the research project, specifying that it involved interviews and observation and if the patient was willing to participate his or her name and phone number was passed along to the researcher.

This method allowed me to enroll 18 patients in the research study. Because the research was designed to also understand how certain relationships might influence decision-making, once a patient was enrolled in the study that patient's network, including primary family members, and hospice workers, were asked to participate in the study as well. Using this method a total of 55 participants were enrolled in this research study: 18 patients, 11 family members/caregivers, 6 nurses, 6 social workers, 8 volunteers, 5 spiritual counselors, and 1 home health aide. Among these participants all patients participated in at least one interview, some participated in several. The other participants were included in a mix of both interviews and/or observation depending on their availability and preferences. Data collection took place in two phases in 2011 and 2012. I used qualitative data analysis software to code both field notes and transcripts of interviews for common themes and topics.

Before beginning the discussion of how hospice patients and their families experience hospice care and dying, I will provide an overview of who these hospice patients are, what they are like, and how they live (See Table 1.1). Although historically hospice care was designed to address the needs of cancer patients, and in some countries such as the United Kingdom it remains geared toward cancer patients, in the United States the majority of hospice patients do not have a cancer diagnosis (National Hospice and Palliative Care Organization 2012). Reflecting these trends the eighteen patients in this study came to hospice with an assortment of diagnoses: lung disease (n=5), cancer

(n=5), heart disease (n=2), Amyotrophic Lateral Sclerosis (ALS) (n=1), Cirrhosis (n=1), and a label of “Debility Unspecified⁴” (n=4).

Most of the patients in the study were in their eighties and nineties with a few in their seventies. The patients in this study spanned from working class to upper-middle class, although the majority appeared to be middle to upper-middle class. All the patients in this study were labeled as White/Not of Hispanic Origin by the hospice staff. Of these patients 10 were some denomination of Protestant Christian, 5 stated they had no religious affiliation, and 3 were Jewish. These hospice patients are unlikely to be representative of hospice patients as an entire populations for several reasons, the most prominent being that they are homogenous in terms of their race and ethnicity, they fall on the higher end of the age spectrum, and have been receiving hospice care for longer than average times (mean 20.6 months/median 11 months). While national estimates by the NHPCO show a mean length of care to be 69.1 days and the median to be even shorter at 19.1 days (National Hospice and Palliative Care Organization 2012). The longer than average duration of hospice care among this sample should be advantageous for this research because it ensures hospice patients have had time to sample the range of hospice services and reach informed opinions about hospice care⁵.

⁴ “Debility Unspecified” is a growing category of hospice diagnosis. As of 2011 13.9% of hospice patients had this diagnosis, which a hospice nurse defined for me as patients who have several ongoing health problems and when combined these problems are causing a decline in their health that warrants a six month prognosis. National Hospice and Palliative Care Organization. 2012. "NHPCO Facts and Figures: Hospice Care in America."

⁵ For example hospice staff reported to me that many short term hospice patients were entirely cared for by a team of hospice staff that managed “crisis care”, they were often in the hospice inpatient facility instead of at home, they were often sedated or unable to communicate for a large part of their time with hospice, and they did not have time to

Table 1.1 Enrolled Patients' Summary Information

Diagnosis			Age		
Lung Disease	5	27.8%	<i>Mean</i>	84	
Cancer	5	27.8%	<i>Median</i>	86.5	
Debility Unspecified	4	22.2%	70-79 years	6	33.3%
Heart Disease	2	11.1%	80-89 years	7	38.9%
Amyotrophic Lateral Sclerosis	1	5.6%	>90 years	5	27.8%
Cirrhosis	1	5.6%			
Gender			Race/Ethnicity		
Female	10	55.6%	White/Non-Hispanic	18	100.0%
Male	8	44.4%			
Religious Background			Marital Status		
Christian	10	55.6%	Married	9	50.0%
No religious affiliation	5	27.8%	Widowed	8	44.4%
Jewish	3	16.7%	Divorced	1	5.6%
Length of hospice care at first interview			Living Situation		
<i>Mean (in months)</i>	20.6		Lives with spouse in family home	7	38.9%
<i>Median (in months)</i>	11		Lives with child in family home	3	16.7%
0-3 months	2	11.1%	Lives alone in family home	2	11.1%
4-6 months	1	5.6%	Lives alone and has paid caregiver	2	11.1%
7-12 months	7	38.9%	Lives in residential care facility	4	22.2%
>13 months	8	44.4%			

The patients in this sample represent a subsample of the hospice population as a whole, but they do portray the breadth of situations hospice patients encounter. Some came to hospice years after their initial diagnosis and illness, some turned to hospice almost immediately. Some patients had diseases that allowed aggressive medical intervention, like cancer, others had diseases allowing no options for a cure, like Amyotrophic Lateral Sclerosis (ALS). More importantly they hint at the broad range of experiences at the end of life that depend on more than just medical care. The patients

develop relationships with hospice workers or use optional services such as hospice volunteers.

differ in respect to their living situation, their family (or lack thereof) and their financial resources. I visited patients in trailer parks and in what could only be called mansions. I visited patients who lived alone and had no family nearby, and others who lived with extended family. Even these summary statistics of how patients live at the end of life do not tell the whole story. Although both might officially live alone, there is a world of difference between the patient who lives in the same apartment complex as her daughter, and the patient whose only children live on the opposite side of the country. There is a substantial difference between patients who live with husbands or wives who can act as caregivers, and those whose husbands and wives are also facing a terminal illness and are incapacitated. This variation, difficult to glimpse from a bird's eye view, becomes immediately apparent in ethnography and paints a picture of how patients and family decisions are embedded in the context of their illnesses and their whole lives.

While this study focused on the decisions of the patients, caregivers, and hospice workers who were interviewed and observed, the goal was to learn more about experiences with hospice and as a result I found myself pleased to hear stories about hospice patients and experiences with dying that were unanticipated. I listened to patients telling me stories about when they were caregivers for a dying parent, spouse, sibling or even child. Volunteers told me stories about the deaths of their parents, husbands, and children both in and out of hospice. Hospice workers told me stories of their own experience as caregivers within their families. Two patients I interviewed were simultaneously hospice patients themselves and acting as caregivers for a spouse in one case and a son in one case who were also hospice patients. In one case a hired caregiver I interviewed was caring for a hospice patient during the day at her paid job, and going

home to another hospice patient, her grandmother, when she went home. So while the bulk of the data gathered in this research is on these 18 patients and those in their social networks, I include stories from all these participants. They are an important reminder that we pass through many different roles and experiences in life. The experiences we face at one point in our lives may very well shape our future choices.

FINDINGS – SOCIAL MEANINGS, SOCIAL CAUSES, SOCIAL DECISIONS

What does this examination of home hospice care teach us about medical decision-making and autonomy? Medical decision-making is a social process. It is not merely social in the sense that medical knowledge and health care systems are socially constructed, it is social in the sense that the motivations and effects of medical care are social, changing how individual lives are lived and how families operate. Medical decision-making is “social” in four distinct ways, which influence the scope and desirability of patient autonomy.

1. “Medical decisions” are socially defined: Many decisions may be a social decision from one point of view and a medical decision from another. Indeed the decision to begin hospice care can be perceived as both a “medical” choice and a “social” choice invested with cultural meaning.

2. Social factors influence medical decisions: The social meaning of hospice, of various forms of care, beliefs about dying all influence what choices patients make. Moreover aspects of a patient’s social setting can enable or constrain choice. Family

concerns, financial considerations, religious and spiritual beliefs all play a strong role in determining what care patients choose and receive.

3. Medical decisions influence social life: Medical decisions are embedded in a social world and affect patients' lives. Decisions about medical care, treatments, or devices have a social impact changing family obligations, patient lifestyle, caregiver workload, and attitudes toward dying itself.

4. Institutional pressures: Institutional forces both help foster and hinder patient choice. Although patients have greater freedom under home hospice care than in many doctor's offices or at hospitals they are still responding to pressures from various institutional forces, notably Medicare, the medical profession (specifically non-hospice physicians), and the hospice institution through the medium of the hospice workers.

Below I provide a brief overview of the findings of this dissertation with an explanation of how each chapter contributes to a new understanding of medicine, illness, and dying.

OVERVIEW OF CHAPTERS

Chapter 1. Hospice Care and the Social Nature of Medical Decision-Making

In this introductory chapter I set the stage for an examination of home hospice care as a magnifying glass into the complex social nature of medical decisions. The point of this chapter is to explain the need for this research, provide an explanation of my methods, a description of the participants, and an overview of my findings. Up until now, scholars who studied end of life medical care and patient autonomy have concluded that

dying patients have little opportunity or desire for control over medical treatments, contesting that they are constrained by medical authority and institutional features. This chapter argues that there is a serious flaw in this research and therefore its conclusions. This research conceives of these choices as “medical decisions” and consequently focuses on the interventions of medical professionals and institutions. In so doing the literature often overlooks the social causes and effects of these decisions. In other words, *the existing literature makes too clean a distinction between medical decisions and social decisions.*

In examining the case of home hospice care I find that many dying patients have both the opportunity and desire to make many significant choices about their medical care at the end of life. Patients generally desire autonomy and when they resist making choices it is not due to deference to medical authority, but instead due to the complex social factors they must weigh in making decisions about medical care. Patients experience an intermingling of social and medical concerns that make it difficult to meaningfully draw a line between medical decisions and social decisions. Although this research involves home hospice care, I suggest that it illuminates social factors common to all medical decision-making, but which are difficult to discern in conventional research in hospital or outpatient settings. I suggest that many of the cases researchers have uncovered of resistance to patient autonomy and apparent deference to medical authority may in fact occur when patients and family members view decisions not as medical, but as social, and they are restricted by their social circumstances. I provide 5 empirical chapters to support this conclusion showing how physicians, patients and their family

members, hospice workers, and external institutions all conceptualize hospice as a social decision.

Chapter 2. Hospice History and the Social Meaning of Hospice Care

What the medical and social science literature commonly treats as a medical decision, patients and family members often view as a social decision. In this chapter I outline a brief history of hospice care as a reaction to the medicalization of dying. I suggest that hospice was intended to be a demedicalizing influence. Using empirical evidence from the study I show that participants in hospice care are more attuned to its social meaning than its medical meaning. They generally conceptualize hospice as a rejection of mainstream medical care, as a form of “giving up” or “choosing dying”. In this sense they see hospice as a social decision about a person's status as living or dying.

Chapter 3. Choosing Hospice or Choosing Dying?

In the case of the referral to hospice care, physicians who act as gatekeepers often encourage the idea that hospice is a social decision not a medical decision. These physicians are often wrongly perceived as the dominant decision-makers. Instead patients often actively choose or refuse hospice care. I argue that patients, family members, and even physicians often describe hospice care not as a medical treatment option, but a social decision or a life choice, often relating it to “choosing dying” or “giving up”. In some cases hospice patients felt hospice care was chosen for them by physician gatekeepers without their active involvement. However, in most cases patients either actively chose hospice or actively resisted doctor's referrals.

Chapter 4. The Social Context of Medical Decisions

Up until now research has predominately focused on the professional and institutional constraints medical institutions place on patient autonomy. This view overlooks the importance of the social context of medical decisions. I note the ambiguity about what represents a “medical decision”. Patients make life decisions, which influence their medical care, and medical decisions, which influence their life choices. Patient choices are both constrained and enabled by immediate social influences, specifically: (1) family considerations, (2) financial circumstances, (3) attitudes toward dying, and (4) and religious and spiritual beliefs. The social context of these decisions suggests that individual level social forces may perhaps be a more powerful determinant of medical decision-making than medical authority.

Chapter 5. Hospice Work: How Social Decision-Making Fosters Patient Autonomy

Until now research has predominately concluded that professional practices and institutional traits foster medicalization and constrain patient autonomy. Hospice is an example of a medical institution in which hospice workers promote patient autonomy by stressing the social relevance of end of life decisions. Paradoxically, hospice workers, while working within a “medical” institution, contribute to the demedicalization of dying by focusing on social concerns. I show how demedicalizing tendencies and holistic care lead to enhanced patient autonomy. Institutional features such as the home setting, interdisciplinary occupational structure, and the type of interactions that comprise hospice work all foster demedicalization, holistic caring, and in turn patient autonomy.

Chapter 6. Conclusion: The Role of External Institutions

Up until now research has focused on how large medical institutions such as the medical profession and Medicare further medicalization. This conclusion ignores the ways in which external forces such as the medical profession and Medicare actually contribute to understanding medical decisions as truly social decisions. This chapter reviews the study findings, noting that a patient's social context also heavily shapes their desire and ability to control medical care and that it may be impossible to extricate medical decisions from social decisions. Understanding a patient's social context and the social meaning of the medical decision may allow a more accurate understanding of how to further the goal of patient autonomy.

Appendix. Notes on Methods, Field Research and Ethics

In the appendix I discuss some of the dilemmas and choices I made in conducting this fieldwork. Ethical questions were of paramount importance as I discussed dying with individuals and family members who were facing death. In this section I reflect on the difficulties inherent in trying to talk to people about dying, and also on the insider-outsider dilemmas I faced as a researcher in this field. I suggest that this study highlights the importance of little utilized methods in research on health care and end of life care: studying patients at home, studying patients in conjunction with their families and health professionals, and combining ethnography and interviews.

FUTURE TRENDS

What do these findings teach us about the role of medicine, illness, and dying in our culture? In broad strokes this research suggests that many of the subtleties of medical care and the illness experience are lost when researchers make too stark a contrast between medical decisions and social decisions or when they analyze medical care in isolation from the rest of patients lives. Just as proponents of medicalization argue that in our contemporary world medicine is interwoven into many unexpected elements of our lives, so we must recognize this by addressing the role of medical care in all contexts and settings. Yet at the same time my research suggests the converse, that the social lives and social context of patients and family members play a bigger part in medical decision-making than much of the literature acknowledges.

This dissertation suggests that not only is medicine and the production of medical knowledge a social process, but in contemporary society medical care intersects with social life in such a way that it can be difficult to meaningfully separate the two. I suggest that medical decisions, in this case hospice care related decisions, are social in four ways. First, medical decisions are socially defined, they are perceived as decisions about social life rather than decisions about medical intervention. Second, social factors specific to the patient and family influence both the patients' and families' ability and desire to make choices about medical interventions, and which choices they make. Third, medical care decisions often influence a patient or family's social life in powerful ways changing their lifestyle and psychosocial status. Fourth, strong institutional pressures influence patient choice. I show that many decisions that might superficially appear to be about medical questions or health are primarily seen as social, psychological, spiritual, administrative,

or even financial. I explore the social motivations and social consequences that guide patient and family decision-making.

One consequence of this study is a reevaluation of the nature of medicalization in health care. My study suggests that complete medicalization may be rare as patients and families are always attuned to the social nature of their “medical” condition and medical treatments. Medicalization is defined as “a process by which nonmedical problems become defined and treated as medical problems” (Conrad 1992, 209), but the critical issue is *who* is defining or treating these problems. Sociologists have long argued that the domain of medicine is expanding and that medicalization is attended by some benefits and many perils (Clarke, Shim, Mamo, Fosket, and Fishman 2003; Conrad 2007; Elliot 2003). However, sociological research tends to focus on medicalizing entities such as doctors, hospitals, and pharmaceutical companies. Unsurprisingly this research finds these entities increasingly define and treat more conditions as medical problems, fostering medicalization. As I show, the patient’s role and perspective is more complex, and suggests both medicalization and demedicalization. The case of hospice care suggests that sociologists have understated a growing movement that is working to demedicalize and care for individuals with illnesses.

Patients experience some medical decisions as primarily social decisions. The decision to start hospice care is generally not a strategic medical decision, but for patients it is a decision about how they perceive themselves – as dying or living. Even within hospice medicalization eludes easy analysis. Patients often see hospice itself and many medical treatments offered through hospice as less medicalizing or even demedicalizing compared to the alternatives. This complexity suggests that medicalization is not an

either or concept, there are forces that are more or less medicalizing and medicalization is subject to perception.

Just as health care has become an omnipresent issue on the national political stage, so it has become a pervasive concern for individuals, particularly those facing a chronic or terminal illness. My research suggests how patients and family members, and surprisingly health care workers and some health care institutions treat medical issues as socially defined and socially managed. While dying has been medicalized in many respects, it and all the myriad choices that accompany it, from which medications to take to whether to transfer to hospice care, are widely perceived as social decisions about a social process with social consequences. Patients and family members who appear unwilling to make medical decisions or who appear to passively accept medical professional recommendations are often actively making a decision they perceive as best for their social circumstances. Any efforts to improve or change the status of patient autonomy must recognize the social context of medical decisions and address the concerns of patients and family members as seen from their perspective.

CHAPTER 2. HOSPICE HISTORY AND THE MEANING OF HOSPICE

This chapter explores the history and meaning of hospice care, a “medical” intervention that is generally perceived by its consumers as a social instead of a medical choice. I outline a cultural history of dying and medicine, and then review the history of the hospice movement and the current state of hospice care in the United States before discussing the symbolism of hospice. The history of the hospice movement suggests that hospice is a response to the medicalization of dying and an effort towards demedicalizing dying. Prior research on hospice primarily treats it as an unsuccessful example of demedicalization and even suggests it has recently become more medicalized.

I show that among participants in this study hospice is perceived as a demedicalizing influence by most patients and families. However, this demedicalization is not seen as positive, instead it is often experienced as a rejection or abandonment by mainstream medicine. This symbolic meaning of hospice care seems to override its pragmatic medical features. I show that hospice is imbued with both a medical meaning and a social symbolic meaning. I argue that the social meaning of hospice predominates, with few participants demonstrating an understanding of the medical strategy of hospice care. The social meaning of hospice emphasizes its demedicalizing qualities, conceptualizing hospice as an alternative when medicine fails or when patients choose to refuse mainstream medicine.

In this sense hospice presents a perfect example of how “medical” decisions, are socially defined by what we deem to be medical. For most participants (at least at the time of referral) hospice does not represent a medical strategy, instead it represents an imminent death. Consequently many patients initially view accepting hospice care as “giving up” on life or “choosing death” in a manner of speaking. Hospice is also seen as a rejection of mainstream medical care, and a shift towards a demedicalization of dying and a prioritization of illness experience. This insight into the meaning of hospice is a precursor to understanding both choices to begin hospice care as well as choices about how one wants to live and die while receiving hospice care.

THE RISE OF MEDICALIZATION AND CHOICE

A brief overview of the history of modern medicine is necessary to explain the origins and goals of the hospice movement. Two relevant trends in the history of medicine explain how dying became perceived as a social problem. The first half of the 20th century saw growing medicalization as the medical profession and medical institutions gained power and prestige. Also during this time period medical paternalism and the objectification of patients became commonplace in conjunction with some abusive practices in medical research and clinical medicine. Subsequently the second half of the 20th century was marked by two trends that were reactions to medicalization and paternalism: a move toward reform and demedicalization marked by increased attention to the illness experience and the growing demand for patient empowerment and

autonomy. These historical changes set the stage for the hospice movement, which valued the demedicalization of dying and the importance of patient autonomy.

A Cultural History of Dying and Medicine

The 20th century saw dramatic changes in social beliefs and practices surrounding dying in industrialized nations. The three most salient changes were (1) epidemiological changes in patterns of death, (2) medicalization (the growing interpretation and treatment of death as a medical problem), and (3) secularization (the decline in religious practices and beliefs concerning dying) (Clark 1993; Davies 2005; Kearl 1989; Seale 1998; Walter 1994). These changes led to a new experience of dying and a new way to respond to dying. The new epidemiological pattern of dying was dying at an advanced age of chronic diseases that might last for years or decades (Seale 2000). The new response to dying was twofold. First, a new industry, medicine, was developed to manage sick and dying individuals. Second, an old response to dying, relying on religious beliefs and rituals to respond to dying and death, waned as a result of secularization.

A brief overview of the history of dying demonstrates how dying was medicalized during the twentieth century, and why hospice care was developed as a response. In 1900 doctors and hospitals were rare and little utilized (Rosenberg 1987). When doctors were called to attend a patient they generally made house calls and there was typically very little they could do to intervene in the process of dying. Dying typically occurred at home surrounded by an extended family. In 1900 you would probably see your grandparents die at home in bed, just as they witnessed their grandparents dying before them. The

work of caregiving was a burden shouldered by the family who helped to feed, bathe, and dress the sick among them. After death the family continued to care for the body of their family member until it was buried (Laderman 2003). After the burial they often visited the graves of family members to pay their respects or simply feel companionship with the deceased (Jupp 1993). There were rituals involved in dying that varied by religion, ethnicity, region, and social class, but were centered on family and spiritual beliefs.

Aries suggests in his history of dying that in 1900 dying was less taboo because it was more familiar and commonplace (1974). It was more familiar because people witnessed it up close from beginning to end in the family home. And it was commonplace because people died more frequently at the turn of the century. Infant mortality was high, maternal mortality was high, and deaths from infections and epidemic diseases were common (Seale 2000). Dying was a process that might take days or weeks, but rarely took years. Dying was not something that only happened to the elderly and sick, it seemed to strike more haphazardly and there appeared to be little that could be done to avoid it. Aries chronicled what he saw as the “*Ars Moriendi*”, the art of dying, a set of practices surrounding dying that predominated in western countries (Ariès 1974; 1981). According to Aries dying was not feared and sequestered as it is today. Instead dying was an accepted and expected part of family life and life in general. While Aries methods and conclusions have garnered much criticism scholars do not dispute that dying today is radically different from its prior manifestations.

During the 20th century patterns of mortality and dying changed dramatically. Social and economic changes led to the urbanization of the United States and other industrialized nations. The expansion and improvement of transportation systems led to

greater geographic mobility. It became more common for the younger generations to spread out across the country and potentially live far away from other family members. The implications for dying are obvious, in a greater number of cases no longer could extended family be relied upon as caregivers for elderly parents. After death pilgrimages to cemeteries and gravestones became more difficult and less common.

An emphasis on public health and the advancement of medical science led to a dramatic change in causes of death. Deaths due to infections and epidemics of diseases such as cholera, typhus, and influenza were eradicated or became very rare. People began to die of heart disease and cancer, diseases that were associated with long life expectancy (Seale 2000). Hospitals proliferated and doctors became accepted as the appropriate managers of sickness and dying (Rosenberg 1987; Starr 1982). Care of sick and dying individuals at home was no longer accepted or expected, instead they were transported to hospitals where they were sequestered. Professional caregivers such as nurses, doctors, and other hospital staff were relied upon to provide much of the hands on care for dying patients. While in 1900 medicine could offer few interventions to cure fatal diseases or injuries, by the dawn of 21st century scientific progress and changed norms led to the expectation that everything possible be done to “save lives” at considerable expense. The expanded options for medical intervention also meant patients and their families were presented with a perplexing array of decisions about receiving care at the end of life. After death occurred bodies were transported to mortuaries and funeral homes (another emergent industry), which then prepared the bodies for the funeral, burial, or cremation (Laderman 2003).

Social beliefs and practices surrounding dying also changed. Aries claims that death became taboo, feared, and sequestered inside hospitals and nursing homes (1974). Many social critics claimed that western culture “denied” death, prizing youth and delusions of immortality at the peril of losing a profound source of meaning in life (Becker 1973). Sociologists have since debated whether we as a society avoid and deny death, the so-called the “denial of death” thesis (Walter, Littlewood, and Pickering 1995; Zimmermann 2004). Advances in medicine and psychology, media representations of death, and secularization are all examined as possible influences on contemporary beliefs about dying (Kearl 1989; Seale 1998). The denial of death came with a steep price. Aries asserts that the fear of dying grew during the 20th century, “The old attitude in which death was both familiar and near, evoking no great fear or awe, offers too marked a contrast to ours, where death is so frightful that we dare not utter its name” (1974, 13). A psychological fear of dying, perhaps an instinctual part of human nature, became more pronounced.

Secularization and declining belief in religious dogma about heaven or other forms of life after death also compounded new social problems with dying (Garces-Foley 2006a). As Berger recounts, in the United States religion used to provide a “sacred canopy” sheltering us all under the same set of principles and shared worldview (1967). Increasing pluralism and the declining authority of religion have led many Americans to feel more doubt about their religious orientation and have contributed to a growing population who may believe in God, but do not affiliate with any religion (Chaves 1994; Hout and Fischer 2002). Unable to rely on religion and clergy as authorities in matters of

life and death (or life after death), professionals who deal with death and dying provide a new source of guidance.

Two dying related industries expanded enormously in the 20th century. Those who dealt with the dying were medical professionals typically ensconced in hospitals. Those who dealt with the dead were undertakers or morticians, ensconced in funeral homes. The funeral home industry had a remarkable effect on attitudes towards dying, bereavement, and appropriate rituals surrounding death (Faust 2008; Laderman 2003; Mitford 1963). Scathing critiques of the industry asserted it was corrupt, took financial advantage of grieving families, and contributed to problematic attitudes toward death through practices such as embalming and preserving bodies to make them appear alive when they are dead (Mitford 1963).

By the mid-twentieth century many critics found contemporary responses to death and dying to be inherently problematic. Death became taboo as it moved out of the family home and into hospitals (Becker 1973). Dying became more complicated as scientific and medical advances created more possibilities for diagnosing, treating, and prognosticating about dying. Cancer became a particularly feared disease due to its lethality, unpredictability, and the fact that people dying of cancer experienced a high degree of pain caused by both the disease itself and treatments such as chemotherapy (Seale 2000, 922). Yet, the two biggest systemic problems with dying were specific to the medical industry. First, like other physiological processes dying became *medicalized* and treated not as a normal life event but as a sign of a biological problem (Conrad and Schneider 1980; Illich 1976). Second, patients became objectified by a paternalistic medical system, which deprived them of the ability to control the experience of dying. The hospice

movement was designed to address these two concerns, first by reasserting dying as a holistic process that should eventually be accepted, and second by empowering patients through a patient-centered approach to care. It is this tension between medicalization and demedicalization, and between paternalism and patient autonomy that explain the rise of the hospice movement and suggests its greatest successes and challenges.

Medicalization

Over the 20th century medicine's purview grew as more human conditions became “medicalized”, defined or treated as medical problems susceptible to the intervention of medical professionals, medical treatments, or medical institutions (Conrad 1992). Medicalization, the expanding scope of medicine, was first conceptualized by Conrad, who focused on the cases of hyperactive children and drunkenness as deviant conditions which previously attributable to “badness” began to be labeled as “sickness” and diagnosed as hyperkinesis (what is now termed ADHD: Attention Deficit Hyperactivity Disorder) and Alcoholism (1976). Among the “problems” medicalized throughout the 20th century included the bookends of human life: birth and death (Lock 1996; Rothman 2007; Teijlingen 2004). Although medicalization is sometimes advantageous to individual patients who welcome a solution to their problems, as a social force it is seen as problematic (Clarke et al. 2003; Conrad 2007; Elliot 2003). Medicalization comes with a high moral, financial, and social cost. In developed nations over the course of the 20th century dying went from being a non-medical event at the turn of the century, to reaching a peak of medicalization in the 1950s and 1960s.

Over time the “engines” or driving forces behind medicalization have changed, as have its consequences (Conrad 2008). In the 1970s and 1980s Conrad listed the rising power of the medical profession, the activities of social movements, and inter or intra-organization activities as the three main sources of medicalization (Conrad 2008, 104-105). Responding to these pressures issues such as hyperactivity, child abuse, menopause, post-traumatic stress, alcoholism, and childbirth came to be defined and treated by medicine. Since the 1980s new forces such as the rising power of biotechnology (e.g. the pharmaceutical industry), rising consumerism, and managed care have prompted the medicalization of issues including anxiety, impotence, genetic abnormalities, obesity, and the rise of cosmetic surgery. In many of these cases not only does agency vanish into the background as people become passive receptacles of disease or genetic imperfection, but medicine and the medical-industrial complex increasingly have the power to define what is “normal” and what is pathological (Conrad 2008, 113). Some theorists argue that medicalization since 1985 has been transformed into biomedicalization, in which there is a more radical intermeshing of technology, science, and medicine in ways that transform human and non-human lives sometimes from the inside out (as through genetic research and manipulation) (Clarke et al. 2003). Yet often missing from these theoretical accounts is an understanding of how the lay public, or patients, perceive medicalization.

Do the public and patients accept the labels and designations of medicine and biomedicine? As Sobal notes, naming is an aspect of medicalization (1995). When fatness became medicalized it became “obesity” (Sobal 1995, 70). However, this shift does not mean that the public stopped using the term fat and universally started treating it

as a medical issue. Likewise when dying became medicalized it was given technical descriptors, dying of “terminal disease” or “incurable disease” or more specifically of “lymphoma”. Even more telling was the shift in how deaths were recorded by coroners, while in the past it was acceptable to list “old age” as a cause of death, coroners are now required to list specific ICD (International Classification of Disease) designations (Kaufman 2005, 82). However, people were still “dying” and in many cases attempts to medicalize cause of death proved problematic⁶. So an important question is *who* labels problems as medical, and *who* accepts or resists these labels?

I argue that the concept of medicalization is neither as simple nor as universal as it appears. I contest that the most important element of Conrad’s definition is unspecified: the question of *who* is defining and treating these problems as medical. There seems to be an implicit assumption that it is the society, or perhaps the “majority opinion of the public, that defines or treats issues such as obesity, alcoholism, impotence, childbirth, child hyperactivity, and dying as “medical”. Certainly scientists and medical professionals define many of these issues as medical, but then it is in their interests to do so and they may be operating to expand their professional jurisdiction. I argue that many if not all of these issues were never fully medicalized. There has always been doubt about how to classify them and whether to consider them as medical or non-medical. In the next section I review what demedicalization means using the example of dying and I argue that just as full medicalization is rare, so is full demedicalization. Medicalization is not an

⁶ Gessert et al show the incompleteness of this type of medicalization – their research on contemporary death certificates that show for the most elderly among us who die the classification of cause of death can be nebulous and imprecise. Gessert, C. E., B. A. Elliott, and I. V. Haller. 2002. "Dying of old age: an examination of death certificates of Minnesota centenarians." *Journal of the American Geriatrics Society* 50:1561-1565.

absolute state, it is a spectrum and likewise demedicalization exists on a spectrum. I suggest that there are many examples of partial demedicalization or demedicalizing influences, and hospice care for dying individuals is one of the most powerful examples.

Demedicalization

Despite the recognition of the perils of medicalization there are very few examples of demedicalization. The professional power and status of the medical profession as well as the corporate weight of players in the medical-industrial complex, such as insurers, hospital chains, pharmaceutical companies, and medical device manufacturers drive our society to further medicalization as it becomes a larger source of market share and profit (Relman 1980).

What does demedicalization mean and what would it look like? Conrad posits a very strict definition of demedicalization: "Demedicalization occurs when a problem is no longer defined as medical, and medical treatments are no longer deemed appropriate" (2007, 7). He provides the examples of homosexuality, which used to be seen as a disease and is now seen as part of a normal variation in sexuality, and masturbation, which used to be treated by doctors and is now seen as normal and not requiring medical intervention. Just as I was critical of Conrad for not specifying *who* defines and treats issues as medical in the process of medicalization the same question arises with demedicalization.

There is ample evidence that many processes that would be described as "medical" by medical professionals were never considered primarily medical to the lay

public. For example, Lock describes how death is socially defined and agreed upon in cases of comatose patients in Japan (2002). In Japan it is family members, not medical professionals, who determine when someone is “dying” and “dead.” In other examples nursing home residents and even medical professionals respond to “social death” (the cessation of social interactions) as a more defining trait of death than biological measures (Morgan 1982; Sudnow 1967). When we turn to examples of issues that are “medical” because they are *treated* (not *defined*) as medical there are even more examples of the rejection of medicalization.

There are ongoing efforts to demedicalize certain issues. There are movements to demedicalize and destigmatize obesity (Sobal 1995). There is a growing trend toward midwifery and childbirth at home (Gaskin 2003; Odent 1984), and more far-reaching a move to re-humanize childbirth in hospitals (Rothman 2007). However, Conrad does not consider these examples of demedicalization, instead he creates a new category for this phenomenon using the terms “resistance” or “reform”. Conrad says, "In the sea of medicalization, there are some islands of resistance. The most successful examples of resistance, such as homosexuality and disability, politicize the issue and make it part of the agenda of a social movement. Sometimes, as with childbirth and perhaps with hospice care for dying, medicalization can be reformed so that its manifestations are no longer as extreme" (2007, 160). I argue that these examples of resistance are pivotal to understanding perspectives on medicalization.

Turning to the example of childbirth, Conrad says childbirth in the United States has been "reformed" not demedicalized, because although it has become more humane since 1950s, pregnancy and childbirth are still defined as medical events (2007, 120).

Changes such as allowing husbands or other family members into the delivery room, making delivery and recovery rooms more home-like, and encouraging women to stay conscious, proactive, and empowered during birth, do not constitute demedicalization. Instead, for demedicalization to occur Conrad says births would have to occur at home and without medical monitoring and with a lay attendant (2007, 120). This type of radical abandonment of medical monitoring and technology is unlikely to occur in our society, yet that does not devalue the reform and resistance Conrad notes. I argue that these reforms and the desire for reform itself is a sign of incomplete medicalization, a sign that issues such as childbirth, and dying have always been seen as holistic conditions involving biological, social, and emotional processes. I suggest that sociologists should focus on these examples, which Conrad calls “resistance” and I call demedicalizing influences. I do not assert processes like dying will ever be fully demedicalized, but I also contest they were never fully medicalized in the first place.

Beginning in the 1960s social critics began to protest the “medicalization” of death, by which dying was defined as a medical problem and not a natural life process (Conrad 1992; Fox 1977; Illich 1976). These efforts never intended to fully demedicalize dying; the goal was not that medical professionals relinquish all involvement in death and dying. Instead the goal was to diminish the medicalization of dying by recognizing and emphasizing that dying is a holistic experience in which psychological, social, and spiritual components are as important as biological changes. Critics such as Timmermans suggest that the hospice movement fell short of its mark in terms of demedicalization

since health care providers still act as “death brokers⁷” in the case of hospice care patients (2005).

The right-to-die and hospice movements have not been able to undermine the cultural authority of healthcare providers to broker deaths. The challenges of alternative dying movements have been absorbed in medical practice and its more radical edges smoothed out. Rather than a drop in cultural authority, the last decades have seen a proliferation of ideal deaths tailored to specific dying situations. Instead of threatening medical professionals, hospice care, sudden death, and even assisted suicide are now firmly under medical control. (Timmermans 2005, 1000)

Yet I suggest that it was never the goal of the hospice movement to separate dying individuals from health care providers. Instead the example of hospice teaches us that patients and their family members have different perspectives on dying than those of medical authorities. That medical professionals broker certain aspects of dying does not mean they control the entire experience. Timmermans use of the term “medical control” is therefore problematic. First, I show in this dissertation that hospice care while it falls under the aegis of “medical care” is representative of a new breed of medical care that emphasizes holistic care and has a demedicalizing influence. Second, I show that patients may attain a high level of control within hospice care where their autonomy is greater than it is in many other form of medical care.

⁷ Timmermans defines death brokering: "Death brokering distinguishes the acceptable line between curing or letting go, achieving a 'good' death and avoiding 'bad' deaths, attributing legitimate responsibility for the death, and determining relevant lifestyle and therapeutic changes to keep on living. Death brokering is a professional accomplishment and, as such, is subject to incursions of competitors and critics on professional jurisdiction." Timmermans, Stefan. 2005. "Death brokering: constructing culturally appropriate deaths." *Sociology of Health and Illness* 27:993-1013.

Medical Paternalism and Patient Objectification

The advance of medicalization did not come without a cost to patients, as the medical profession gained power patients increasingly lost power and became objectified. Growing medical paternalism and patient objectification during the first half of the 20th century were an impetus to change, leading to the push for patient rights and patient autonomy.

What historical changes led to these fluctuations in the patient-doctor power structure? Prior to the “Golden Age of Medicine” and throughout most of human history what “medical” care was available was provided in patients’ home where the patients were patrons and the doctors were their clients (Berliner 1982). During most of history medical science was relatively rudimentary and unable to influence the course of most diseases. During the 20th century the growth in medical knowledge, the growth of the medical profession, and the corporations and institutions that support it all shifted the power balance in the medical encounter (Starr 1982). A boon in medical research and discoveries after World War II led to a new mastery over infectious diseases and epidemics. Clinics, hospitals, medical schools, and medical research gained funding and prestige. By the 1950s most medical care was provided at hospitals or outpatient clinics. Medical knowledge had grown so complex and esoteric that the public could not understand it without doctors to interpret it for them. The medical profession, insurers, and hospitals were powerful players with resources at their disposal, while patients were disempowered by their lack of medical knowledge, lower status position, and reliance upon medical professionals to guide them. Most patients accepted this “sick role”, in

which they obeyed the doctor's orders without question with the tacit agreement that if they followed medical advice they would be healed (Parsons 1951, 436).

During this "Golden Age" of medicine, and still today in many respects, patients were not treated as competent adults with full lives. Instead the paternalistic relationship conceptualized patients as more like children who must obey the doctor and "comply" with their interventions in order to recover. Physicians regularly made critical decisions for patients who they felt were unable to make such difficult decisions. Physicians rarely revealed to patients that they had cancer or other terminal illnesses (Glaser and Strauss 1965; Oken 1961). Patients were also excluded from most therapeutic decisions because the "doctor knows best" how to treat diseases. Moreover, patients' values and feelings were often disregarded by physicians who treated them as "diseases" not people. As Arthur Frank relates in a contemporary autobiographical example, during his own hospitalization for cancer he heard medical staff referring to him as "the lymphoma", instead of by name (1991, 52). As the evidence for problems with this paternalistic system began to mount a new movement began to re-affirm patients' rights and empower patients to make health decisions.

PATIENT EMPOWERMENT AND THE PRINCIPLE OF PATIENT AUTONOMY

Medical paternalism and patient objectification had a dark side. A range of abusive practices and unethical research studies exposed how patients were often harmed in the pursuit of scientific knowledge (Beecher 1966; Rothman 1991). The example of the Tuskegee Syphilis Experiment was perhaps the most well known case of a

disadvantaged group, poor black Southern men, who were part of a research study that denied them knowledge of their condition, syphilis, and actively prevented them from being treated for this life-threatening disease (Brandt 1978). In other cases it was not medical “research”, but medical “practice” in which physicians discriminated and harmed certain groups of patients. In some cases physicians made moral judgments about the value of a patient’s life and whether to provide medical intervention based on superficial information such as whether a patient was homeless, drunk or used drugs (Sudnow 1967). As these abuses became known there was an increasing demand both among medical professionals and the public to empower patients.

The decision whether or not to inform patients of their diagnosis and prognosis and whether to give them treatment options became an ethics issue as critics in the 1960s exposed the flaws with current practices that objectified and infantilized patients (Glaser and Strauss 1965; Oken 1961; Sudnow 1967). The new field of bioethics was born amid a flurry of professional and political effort to protect and empower patients (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research Beauchamp and Childress 1979; 1979). Four bioethics principles became acknowledged as essential to the practice of medicine: respect for autonomy, nonmaleficence (doing no harm), beneficence (doing good), and justice (Beauchamp and Childress 1979). While the medical profession ostensibly must attend to each of these principles, much of the intellectual debate has centered on the topic of patient autonomy and how to empower patients and has overlooked the question of the goals medicine and patients pursue (Evans 2002).

Social movements fighting for civil rights and women's rights buttressed the movement for patients' rights and patient empowerment. Particularly influential was the feminist critique of the patriarchal health care system, embodied in a book called Our Bodies, Ourselves (Boston Women's Health Book Collective 1973). Other health social movements flourished in later decades organizing to advocate for individuals with specific diseases or conditions such as AIDS or breast cancer (Epstein 1996; Klawiter 2008). Notably the right-to-die movement and the hospice movement began to flourish in the late 1960s and early 1970s in response to this political climate (Filene 1998; Saunders 1980).

Physicians took an active role in these debates about the extent and intent of patient autonomy. Many physicians suggested that while historical paternalism imposed too great a limit on patient authority, full patient autonomy or control of medical treatments is both undesirable and impractical. Most physicians conceived of the patient-physician relationship as flexible and patient autonomy existing on a spectrum. They asserted that depending on the type of medical problem physicians might vary in their decision-making style and how much they include the patient in the process (Emanuel and Emanuel 1992; Quill and Brody 1996). Other analyses emphasize that physicians' "clinical judgment" includes making many "silent decisions" that should not be subject to the patient's input (Whitney and McCullough 2007). Many of these debates revolve around whether the goal of patient autonomy should override other concerns such as nonmaleficence, a question that often arises in cases related to the "choice" to die as in euthanasia or physician-assisted suicide (Fried, Stein, O'Sullivan, Brock, and Novack 1993).

Many of the debates surrounding patient empowerment and the principle of patient autonomy revolved around issues of life or death (Rothman 1991). New “life support” technologies such as respirators, feeding tubes, resuscitation, and organ transplants raised perplexing new questions about when and on whom these technologies should be used. While the principle of patient autonomy should in theory apply to all health care decisions, practically it frequently arises in questions concerning end of life care and “life support” (Drought and Koenig 2002). While the paradigm of patient autonomy developed its own institutional life and devices, evidence suggests the practice of patient autonomy never lived up to the ideal (SUPPORT Principal Investigators 1995).

However, patients found other ways of empowering themselves and changing the health care system. Notably health social movements challenged and changed medical knowledge itself. Epstein shows how lay-experts can join the “credibility struggles” which create medical knowledge and have a large impact on clinical research and health outcomes, as in the case of AIDS activists (1995; Epstein 1996). Epstein, like other scholars points to how social movements can democratize medicine and empower patients. However, despite changes to policy and best practices, the study of activists and reform overlooks the more subtle and sometimes more powerful way in which individuals shape their health and their medical destiny.

There is another form of power that is more difficult to glimpse and happens on an individual scale. Patients make choices every day. Studies of consumerism in medicine suggest the extent to which patients today are accustomed to selecting some aspects of their care; which drug to take, whether to pursue Complementary or Alternative Medication (Chapkis and Webb 2008), and whether to consider plastic

surgery or “enhancement” (Elliot 2003; Loe 2004). Exploring consumerism focuses on domains in which patients clamor for choice and control. The social and cultural context of these decisions is made clear in analyses that explore the social meaning of impotence in relation to the rise of Viagra (Loe 2004), or the use of plastic surgery to change racialized body features (Kaw 1991). Increasing medicalization creates a new world of choices for consumers by creating new diseases and medical products to market to individuals who want to change some aspect of themselves.

These opposing trends set the stage for hospice. Medicalization stresses the growing power of medicine and its institutions. Meanwhile the growing attention on patient autonomy attempts to check this power and shift the patient-physician power balance. I argue that the hospice movement is a response to both trends; it is an effort to redress the medicalization of dying and to further the goal of patient autonomy.

THE BIRTH OF THE MODERN HOSPICE MOVEMENT

It was during this period of growing medicalization and growing disenchantment with hospital care for dying patients that modern hospice care was created⁸. As Siebold describes the history, “Two women, Drs. Cicely Saunders and Elisabeth Kubler-Ross, were among those who asserted that dying had become a social problem, and they recommended an alternative to traditional medical care” (Siebold 1992, 2). The modern hospice movement was a reaction to problems with hospital care for dying patients, such

⁸ Siebold presents a compelling argument that hospices as institutions catering to dying individuals have been around for centuries, but it is commonly acknowledged that the form, content, and scope of hospice care was revolutionized in the 1960s and 1970s. Siebold, Cathy. 1992. *The hospice movement: easing death's pains*: Twayne.

as lack of attention to patients' physical pain and psychological suffering (Kubler-Ross 1969; Saunders 1963). The hospice movement was also a reaction to social attitudes towards dying, specifically the medicalization and objectification of dying patients. The hospice movement opposed the two problems outlined above: medicalization and paternalism. It opposed medicalization by conceptualizing dying as a natural life process, which should be accepted and not fought. It opposed paternalism by treating patients holistically, as persons not objects or diseases.

The birth of the modern hospice movement⁹ is often attributed to the pioneering work of a doctor from the United Kingdom, Dame Cicely Saunders, who led an international social movement with the vision of improving care for dying patients (Siebold 1992). She founded the first modern hospice, St. Christopher's in 1967, and its current website proclaims that with its founding "A holistic approach, caring for a patient's physical, spiritual and psychological wellbeing, marked a new beginning, not only for the care of the dying but for the practice of medicine as a whole" (2007). In the United Kingdom hospice care was exclusively for cancer patients and took place in an inpatient facility, the hospice, where patients resided until their death. The hallmark of hospice care was its focus on palliative *care*, instead of *cure*-oriented (curative) treatments. Patients who could not be cured, or who declined treatments, received hospice care to relieve pain and discomfort. Dr. Saunders was instrumental in revolutionizing pain control for dying patients, by formulating, advocating, and training others in the use of morphine for dying patients. It was this skill in addressing pain and

⁹ Hospices were in existence before 1967, in fact they have their origin in religious institutions during medieval times. However, hospices underwent an overhaul and rebirth in the late 1960s, and a new type of hospice was created and became widely popular.

the provision of holistic care, focusing on physical discomfort and psychological, social, and spiritual concerns that made hospice care distinct from other care for dying patients.

However, hospice was more than just an innovation in the provision of medical care. Hospice represented a philosophy on dying, and hospice was a social movement intended to improve the experience of dying. Hospice care is based on the underlying belief that a “good death”, or at the very least a “better” way to die, is possible (Byock 1997). The idea of a “good death¹⁰” is what Kaufman dubs a “cultural ideal”, and it typically includes such traits as dying at home surrounded by family, dying after a long life, dying at peace, and dying without pain and suffering, in its definition¹¹ (Kaufman 2000). The hospice philosophy emphasizes that dying is both a physical and a psychological journey. Hospice focuses on dying patients' (and their family members') total quality of life, including what Dr. Saunders called “total pain”, including physical, emotional, social, and spiritual suffering (Clark 1999; Saunders 1963). Dr. Saunders' British hospices were unabashedly Christian institutions and religion and faith were embedded in hospice practices. As I demonstrate in the next section the social definition

¹⁰ Kaufman describes the “good death” and “death with dignity” as “phrases [which] express a cultural ideal, in which dying persons can freely reject use of medical technologies that prolong the dying process, are able to manage their own pain, and can control the environment (home, hospice, hospital) of their deaths” Kaufman, Sharon. 2000. “Senescence, decline, and the quest for a Good Death: contemporary dilemmas and historical antecedents.” *Journal of Aging Studies* 14:1-23.

¹¹ In another summary of beliefs about the good death, Gott et al suggest that it is: “pain-free death; open acknowledgement of the imminence of death; death at home, surrounded by family and friends; an “aware” death in which personal conflicts and unfinished business are resolved; death as personal growth; and death according to personal preference and in a manner that resonates with the person’s individuality” Gott, M., Neil Small, Sarah Barnes, Sheila Payne, and David Seamark. 2008. “Older people's views of a good death in heart failure: implications for palliative care provision.” *Social Science and Medicine* 67:1113-1121.

of hospice, based on interpretations of the hospice philosophy, precedes and often supersedes its medical definition.

The hospice philosophy was intended to change how individuals and society react to death. As Dr. Saunders writes, “The [hospice] movement has been prepared to look death - the great taboo subject of our age - squarely in the face and to encourage the dying and their families and all those caring for them to do the same.”(1980, 1) In other words Saunders believed an important part of the hospice mission and the dying process was to face death and to accept dying. This insistence on “accepting” death was also being publicized by Elisabeth Kubler-Ross another prominent female physician and researcher who was a charismatic leader in the field of Thanatology, and like Saunders lectured and trained others widely. Kubler-Ross’s book, On Death and Dying, provided a window into the experiences of dying patients at a Chicago hospital (1969). Their pain, sadness, and changes in their outlook toward dying were recorded by Kubler-Ross in interviews. She concluded that dying patients were neglected, ignored, and often lose their personhood, becoming objects, “He [the patient] slowly but surely is beginning to be treated like a thing. He is no longer a person” (Kubler-Ross 1969, 9). She interpreted her findings into a theory that dying occurs in five psychological stages: (1) denial and isolation, (2) anger, (3) bargaining, (4) depression, and (5) acceptance. Despite many criticisms of her stage theory, failures to replicate it, and attempts to debunk it, it remains a strong component of lay beliefs about dying. The idea that the final stage of dying is acceptance resonates with people and forms a foundation for the hospice philosophy.

While the hospice movement never intended to remove medical treatments from dying individuals, it was intended to be a demedicalizing influence. Hospices were noted

for the qualities that set them apart from mainstream medical care: a home-like environment, compassionate and caring staff and volunteers, and a focus on not just the patient but his or her family members and friends. Although full demedicalization was never its goal, indeed use of pain medication was central to the hospice mission, hospice attempted to place the biological process of dying within the larger framework of a natural life process which also involved psychological, social, and spiritual processes.

While the modern hospice movement started in the United Kingdom, Dr. Saunders lectured and trained medical professionals widely, and by 1974 the first hospice was founded in the United States and many soon followed (Connor 1998; Siebold 1992). While these early hospices were largely funded by private donations and staffed by volunteers, as time passed in both the United Kingdom and the United States the success of hospice care and its cost-effectiveness gained them government funding. Today hospice care involves many participants: nurses, social workers, family caregivers, home health aides, doctors, bereavement counselors, administrators, and volunteers, etc. Hospice care has expanded around the world, with a strong foothold in developed countries and a growing presence in countries stricken by poverty and accompanying high mortality from causes like AIDS (Clark 2007). For a description of current hospice programs in the U.S. see Table 2.1. Hospice care also takes place in various settings, such as family homes, hospice facilities, hospitals, and nursing homes, although in the U.S. most hospice care takes place in private homes and nursing homes (see Table 2.2).

Table 2.1 National Program Level Data – Hospice Care in the U.S. in 2011

Number of hospice programs in the U.S.	5,300*			
Type of hospice provider	Free Standing/Independent	57.5%	Part of Home Health Agency	16.8%
	Part of Hospital System	20.3%	Part of a Nursing Home	5.2%
Hospice program size: based on patient admission per year	< 49	15.4%	151 to 500	34.2%
	50 to 150	29.3%	> 501	21.1%
Hospice program tax status	Not for profit	34.0%	For profit	60.0%
	Government	5.0%		
Distribution of paid staff***	Nursing	38.0%	Other Clinical Staff	1.9%
	Non-Clinical/Administrative	21.3%	Bereavement Staff	4.3%
	Home Health Aides	18.8%	Chaplains	4.3%
	Social Services	8.6%	Physicians	2.9 %
Percentage of Patients served by Payer	Hospice Medicare Benefit	84.0%	Private Insurance/Managed Care	7.7%
	Hospice Medicaid Benefit	5.2%	Other Payment Sources**	3.1%
<p>Estimates from National Hospice and Palliative Care Organization 2011 Data Collection. * Including Puerto Rico, Guam, and U.S. Virgin Islands. **Includes uncompensated/charity care (1.3%), self pay (1.1%), and other payment sources (0.7%). ***Does not include non-paid staff such as volunteers, in 2011 there were an estimated 450,000 hospice volunteers nationwide.</p>				

In the 1970s and 1980s hospice care was often seen as an alternative to mainstream medicine, and as a form of opting out of traditional care, however in the last twenty years hospice care has been redefined as mainstream. Since 1983 Hospice care has been a covered Medicare benefit (United States Congress 1982), and today 89.2% of hospice care is paid for through public funds, primarily through Medicare (National Hospice and Palliative Care Organization 2012). Medicare coverage of hospice care

transformed the industry and the number of hospice programs has skyrocketed since 1983¹² with approximately 5,300 hospice programs operating in 2011 (National Hospice and Palliative Care Organization 2012). Because Medicare rules allow any patient to receive the hospice benefit as long as doctors give an official prognosis that the patient has six months or less to live, hospice care in the U.S. is now used by patients with a wide variety of diagnoses (See Table 2.1). While in 1992, 78% of hospice patients had cancer diagnoses, in 1995 60% were cancer patients (Connor 1998, 6), and by 2011 a minority of patients, 37.7%, had cancer diagnoses (National Hospice and Palliative Care Organization 2012).

For many years hospice care was seen as an outsider in the world of mainstream medicine. However, the advocacy of hospice physicians and the growing clinical evidence suggesting the great value of hospice care has begun to change this dynamic and bring hospice and Palliative Care into the fold of conventional medicine (Smith, Temin, Alesi, Abernethy, Balboni, Basch, Ferrell, Loscalzo, Meier, Paice, Peppercorn, Somerfield, Stovall, and Von Roenn 2012). In 2006 “Hospice and Palliative Medicine” was made a sub-specialty by the American Board of Medical Specialties, solidifying the medical profession's official support of this form of care (Quest, Marco, and Derse 2009; von Gunten and Lupu 2004). Today, 39 years after the first hospice opened in the U.S., nearly half of all deaths occur at home, and hospice care is now a mainstream method of

¹² The first U.S. hospice, Hospice Inc., was founded in Connecticut in 1974. In 1978 the National Hospice Organization (now the National Hospice and Palliative Care Organization - NHPCO) was founded and listed 1,200 hospice programs in its national directory. Connor, Stephen R. 1998. *Hospice: Practice, pitfalls, and promise*. Washington, D.C.: Taylor and Francis. A report released by the NHPCO estimates that there were 5,300 hospice programs operating in 2011. National Hospice and Palliative Care Organization. 2012. "NHPCO Facts and Figures: Hospice Care in America."

caring for patients and families during the dying process. Although hospice care is now embedded in the structures of mainstream medicine, such as Medicare, in the next section I show that its social meaning as a rejection of medical care still predominates over its medical connotations.

Table 2.2 National Patient Data – Hospice Care in the U.S. in 2011

Total hospice patients served	1.65 million patients (44.6% of recorded deaths)			
Length of hospice services	Mean:	69.1 days	Median:	19.1 days
Place of death	Private residence	41.6%	Acute care hospital	7.4%
	Nursing home	18.3%	Residential facility	6.6%
	Hospice inpatient facility	26.1%		
Gender	Female	56.4%	Male	43.6%
Patient Age	< 35 years	0.8%	75-84 years	27.6%
	35-64 years	16.0%	> 85 years	39.3%
	65-74 years	16.3%		
Patient ethnicity:	Non-Hispanic	93.8%	Hispanic	6.2%
Patient race:	Caucasian	82.8%	Asian, Hawaiian, or Other Pacific Islander	2.4%
	Black/African American	8.5%	American Indian or Alaskan Native	0.2%
	Multiracial/Other Race	6.1%		
Patient primary diagnosis:	Cancer	37.7%	Dementia/Alzheimer's	12.5%
	Heart Disease	11.4%	Other Diagnoses	15.9%*
	Debility Unspecified	13.9%	Lung Disease/Chronic Obstructive Pulmonary Disease	8.5%

Estimates from National Hospice and Palliative Care Organization 2011 Data Collection.

* Other diagnoses: Stroke or Coma 4.1%; Kidney Disease/End Stage Renal Disease 2.7%; Non-ALS Motor Neuron Diseases 1.6%; Liver Disease 2.1%; HIV / AIDS 0.2%; Amyotrophic Lateral Sclerosis (ALS) 0.4%; Other Diagnoses 4.8%.

THE SOCIAL MEANINGS OF HOSPICE

The above review of changes in medicine and in the sphere of death and dying illustrate how the hospice social movement and institution is a demedicalizing influence that was intended to improve patient experience. This historical meaning of hospice in a wider historical-institutional context is clear, but without exploring the perspective of real hospice patients it is impossible to know what social meaning hospice has for them. I find that for most patients hospice has a primarily social meaning, not a medical meaning. While hospice may be an example of medicalization in that Medicare and physicians judge it to be a medical intervention, the majority of patients focus on its social meaning, which is demedicalizing. These patients generally see hospice as a rejection of medicine and as “choosing to die”.

Other attempts to chronicle the meaning of hospice and the experience of hospice patients show complicated and often contradictory meanings of hospice care. Lawton’s ethnography of a inpatient hospice and day-care unit in the United Kingdom finds both a loss of personhood and loss of self as characteristic of the hospice population (2000). Lawton offers a critique of the social movement conceptualization of hospice, arguing that the hospice patients she sees have or are transitioning from experiencing their body as subject to their control to body as object over which they have lost control. In her telling hospice care is not empowering, but about the erosion of patient autonomy and selfhood. Lawton contests ideological notions of hospice care, saying “What seems to be ‘glossed over’ or ignored within the hospice model, then, is the bodily realities of a patient’s deterioration and decline: realities which, as we shall see, make it very difficult to enact the goals of hospice care in practice” (2000, 16). In Lawton’s analysis the

experience of hospice care, while involving medical treatments, is mainly about psychosocial loss of self.

However, another analysis by Broom and Cavenagh suggests that it may be the inpatient facility itself that fosters this loss of self since it functions as a liminal space, “bereft of the recognized parts of one’s self, home, and identity” (2011, 106). While these studies raise important questions about the possibility of demedicalization and patient empowerment in inpatient hospice facilities, they do not inform us about the large portion of hospice care which occurs at home. I now turn to a description of how home hospice patients in this study interpret the meaning of hospice care; for them the meaning of hospice is not primarily about medical care, it is about attitudes toward dying.

While the hospice movement espouses the virtues of demedicalization and acceptance of dying, as I show below, hospice patients, their family members, and other individuals unfamiliar with hospice interpret hospice care more negatively as “choosing dying”, implying that one has a choice and is turning one’s back on life. This dominant meaning of hospice equates hospice with imminent death and hastened dying and often inspires fear. In this common usage hospice is equated with “giving up”. Either a patient is “giving up” hope for a cure, or a doctor is “giving up” on a patient by turning him or her over to hospice. Closely related is the idea that hospice represents a failure or defeat, a failure of modern medicine to cure a patient and a defeat for the patient.

A second more positive but subordinate meaning of hospice is learned upon familiarization with hospice and situates hospice within the larger framework of medical care. This subordinate meaning conceptualizes hospice as a form of medical care that not only improves the experience of dying, but often improves both the patient’s quality and

quantity of life. Understanding these competing perspectives on the meaning of hospice is an important precursor to understanding the choices patients make (and resist making) with regards to hospice care.

In summary, I find there are two common meanings of hospice care. (1) Hospice as choosing dying: this is the dominant meaning and equates hospice with a social attitude not a medical strategy. (2) Hospice as about living: this is a subordinate meaning in which hospice is about providing medical care to help patients live better (and have more “quality of life”).

Hospice as Choosing Dying

Most patients in this study at the time of their referral to hospice had a minimal understanding of what medical care hospice provided, instead to them hospice had a social meaning; it meant they were ready to die. While the hospice philosophy emphasizes the positive virtue of “accepting dying”, for most Americans today the idea of hospice suggests another action, “choosing dying.” This meaning of hospice care makes it an emotionally and socially difficult choice.

Why do so many people associate hospice with choosing dying? The word “hospice” itself evokes many of these negative connotations. Unlike care in a hospital, hospice care is typically a one-way street. People go to hospitals for many reasons: to repair a broken leg, for childbirth, to be fixed or cured, and sometimes to die. People are admitted to hospice for only one reason, they are believed to be dying. Hospice is therefore an emotionally laden word; it brings with it all the beliefs, fears, and

expectations we have about dying. Since only a small segment of the population has experienced hospice care firsthand and dying is not a topic many people freely discuss, misconceptions and lack of information about hospice abounds among both the general public and physicians (Gazelle 2007; Mor, Hendershot, and Cryan 1989).

Dying is a poorly delimited concept, in part because physicians do not adequately focus on prognostication (Christakis 1999). Unlike the cessation of the heartbeat as an indicator for death (Lock 1996), there is no agreed upon biological indicator for dying or the phase of “liminality” between life and death (Kaufman and Morgan 2005). Sometimes death happens almost instantaneously, as in the case of violent deaths such as car accidents or murder. More often in contemporary society we die slowly, and dying is itself a gradual process often due to progressive illnesses like cancer, heart disease, lung disease, or dementia. Although phrases such as “terminal illness”, with its connotation of impending death, are part of our public discourse, they are not necessarily used when doctors speak to patients or their family members. Sometimes the first confirmation patients and family members receive that they are actually dying is when a physician mentions “hospice care”.

Many patients were probably aware of their terminal diagnosis before their referral to hospice care. Indeed Kellehear’s research on cancer patients suggests that as many as 53% suspect or believe they are dying before receiving an official diagnosis or prognosis from a physician (1990). However, for some patients the referral to hospice and revelation of terminal illness happen in the same encounter. Often patients are never given a clear prognosis by physicians, a problem chronicled by Christakis who explains

the dire consequences for the patients and families who are never referred to hospice, referred too late, or who are otherwise unable to prepare for their death (1999).

For many patients in this study the word “hospice” when spoken by physicians seemed to them to be a code word for “dying”. Even for patients who know or suspect they are dying, the word hospice and the label of “hospice patient” forces a new recognition of exactly how limited their time may be. To meet Hospice Medicare eligibility requirements doctors must certify that a hospice patient has a prognosis of six months or less to live. Doctors are not required to reveal this prognosis to patients, but many patients understand a referral to hospice means they are being told they have six months or less to live. In this sense the medical profession has sanctioned a specific definition of dying to be applied to hospice care, a definition for a concept that is poorly delimited elsewhere. Because of this association between hospice and dying, the word hospice, indeed the idea of hospice, when first introduced to patients and their family members often provokes fear, stigma, sadness, and defeat. Many see enrolling in hospice as acknowledging, accepting, choosing or even hastening dying.

The word hospice carries a strong stigma in our society. People with some knowledge about hospice tend to associate it with a place, a facility like a hospital, with morphine, heavily sedated perhaps unresponsive patients, and cancer. Misconceptions about hospice abound. For example, Henri¹³ a Pacific Hospice patient and a former

¹³ Henri is a pseudonym as are all the names of participants in this study. The names of doctors, family members, and other individuals they refer to are also changed as well as any identifying characteristics.

hospital emergency department physician who had dealt with hospice often in his professional life, says many people think hospice tries to “kill you off¹⁴”.

There is a common belief that hospice patients are almost always at death’s door with only days to live (Gazelle 2007), a misconception even hospice workers admit to sharing. Loren, a hospice massage therapy volunteer describes her misconceptions and her first experience with a hospice patient.

The first time I ever went to give somebody a massage, I was actually surprised how well he looked. He looked better than a lot of people I see walking around. So, I was kind of shocked and was like, oh okay, I thought it was going to be a very sick person. So, my expectations then were really different from now and I had to kind of improvise, you know, how to give him the massage given that I just—I expected him to be very far along and advanced in his disease and he wasn’t. He had never had a massage before and I didn’t bring my table because I thought—I don’t know why I thought that he was going to be bed bound.

Loren quickly learned that many hospice patients are still very active and mobile, and may experience long periods of relatively stable health before they finally decline. Yet time after time in my discussions with hospice patients, family members, and hospice workers they admitted that when they first heard of hospice they thought it meant that they would die within days or at the most weeks. Even hospice staff started out with many of these misconceptions. Ellen, a longtime Pacific Hospice nurse describes her initial reaction to the job of being a hospice nurse. At the time her father was receiving hospice care and she was speaking to his hospice nurse.

I was amazed. I said that must be so hard on you because your patients are always dying. And she said, well no. I said, what do you mean ‘no’?

¹⁴ Indeed in many instances hospice seems to be conflated with the right-to-die movement and political efforts to legalize euthanasia, physician-assisted suicide or other measures.

They're on hospice? And she said, well you don't have patients die every day. She said, you have patients for months at a time, and eventually yeah they do die because they're terminal. But she said it's not an every day thing for us. And I said, oh okay.

For Ellen, who was employed as a hospital nurse at the time, she shared the public stigmatized idea of hospice, and it was only her personal experience with hospice that changed her outlook and eventually led her to pursue a career as a hospice nurse. In this dominant meaning of hospice, it does not evoke a form of medical care, instead it evokes the idea that the patient is ready to or about to die.

The label of “hospice patient” likewise has a social meaning. It does not suggest what medical care a person is receiving, instead it merely connotes that a person is close to dying. Colleen, a volunteer who works with a patient in this study, and whose mother also received Pacific Hospice care describes how she acted as an advocate to ensure her mother received hospice care and then still found herself shocked when her mother was officially labeled a “hospice patient”. Colleen made it a point to research hospice care, to go to her mother’s doctor’s appointments, and finally to write a letter to her mother’s doctor explaining why she thought her mother should receive hospice care. The doctor agreed to refer her mother to hospice and here Colleen describes when the admitting nurse came out from Pacific Hospice to assess whether Colleen’s mother was eligible for hospice. This long segment of our interview captures some of the complexity involved in becoming a “hospice patient”.

Colleen: So Hospice came and there is a person who we never saw again. Her job is to be the gateway to the nurse and so she did a few -- took some vitals, and I really didn't think she was going to qualify because my mom

was -- though she was diagnosed with COPD and needed gradually more and more help because, you know, your lungs are turning trash and things that you could do a month ago slowly, inexorably you can't do as much as you go on... And the nice lady came, and it was a close call. She wasn't sure. She called a doctor who was on staff and ready to take questions and so on, and they accepted her. And I had an interesting emotional response to that. Part of me was shocked even though I had very rationally seen what was going on, wrote my letter to the doctor and so on, everything was being done in a rational manner. And then the Hospice person came and my mother was a Hospice patient. I couldn't believe it. Mom and I were both surprised and we thought they were wrong. We both reacted like -- it's like we're taking on this role it's like you're kidding, right? We couldn't believe it.

Interviewer: ...there's an association of what a Hospice patient...

Colleen: Well six months to live, right? The fact that they accepted her as a Hospice patient made the whole idea of death more real than either of us were prepared for. It was sort of like somebody saying yep, you're right; whereas before it was more like we were being rational but it didn't seem real. I don't know how to put it to you better than that.

Interviewer: No, I understand that. That's...

Colleen: Mom was very matter of fact. Both of us are very matter of fact people. But nevertheless, we were both kind of surprised by it. We expected them to say no. Anyway, so they accepted her.

If both Colleen and her mother could still find themselves shocked and dismayed when officially accepted and labeled as a hospice patient, despite the fact that they actively sought out hospice care, it should come as no surprise that for most people their first reaction to a referral to hospice is fear. Although her mother's health was clearly declining, no medical professional had ever given her mother a prognosis of months or years to live, and no one had labeled her as "dying". Nevertheless her acceptance into the hospice program was itself a status change, a passage from someone with a chronic illness to someone who is dying.

“Hospice” appeared to be almost a code word for dying in the illness narratives of patients in this study. When asked about their diagnosis and the progression of their illness, very few patients reported that doctors told them they were dying or gave them a prognosis in months, instead doctors would suggest hospice¹⁵. Many of these conversations with physicians took place months if not years before I met with patients, and I have no way of knowing what was actually said in these conversations. However, what is important is how patients remember these events and for many the mention of hospice was a watershed moment. When you are labeled “hospice eligible” or a “hospice patient”, suddenly you start to think about yourself as dying instead of living.

Lutfey and Maynard describe a similar phenomenon in which hospice is used as a code word by physicians for revealing to patients that they have a terminal prognosis (1998). As one oncologist in their study states, “Sometimes I use the discussion of hospice not so much because it’s important to me that the patient accept a home hospice program, but it’s a way of introducing them to the idea that they’re - of how sick they are, really. So I was trying to use it more as a platform... that’s sometimes a good idea to get the conversation really directed where you want it to go, which is on death and dying issues” (Lutfey and Maynard 1998, 325). In this example the oncologist stops just short of saying that patients are dying, perhaps indicating a personal and professional uneasiness about discussing death and dying. The above examples illustrate how hospice is equated with an imminent death, but it is also associated with “choosing” death or

¹⁵ As one palliative care physician and researcher pointed out to me, Medicare regulations require doctors give a prognosis of six months or less, but there is no requirement that patients be informed of this prognosis (Dr. Alex Smith personal meeting 5/22/2012).

“giving up” on life. The meaning of hospice to these participants is not about medicine so much as it is a commentary on a person’s proximity to death.

Hospice as Defeat and “Giving Up”

The dominant meaning of hospice among patients in this study, particularly when describing their feelings when they began hospice care, was that hospice represented giving up and choosing death. There is a mindset that, as one Pacific Hospice nurse, Stacey described it, “hospice is defeat”. Again, hospice is not defined by its strategy for medical intervention, but instead it is defined as when medicine is defeated or rejected. This conception of dying as defeat seems to be in part the consequence of medicalization of dying, and part a natural human response to what Berger and Luckmann characterized as the force most threatening to the social whole: death (1967). Even the hospice nurse Stacey, who is a strong advocate for hospice admits when it is her time she might feel like starting hospice care is a defeat: “Even myself by the time I’m you know like send me, God willing, for whatever my journey takes me for my death, if I have some terminal illness and have been told there is nothing else we can do, with all my history in the hospice philosophy, I still would probably feel like going on hospice, there is going to be an element of just defeat, of giving up in a way.” The association between hospice and defeatism gives it a negative social meaning.

For people unfamiliar with hospice the word “hospice” provokes a negative reaction. Many hospice workers, paid staff and volunteers lamented to me that family and friends resisted talking to them about their work because they found it “depressing”.

Samantha, a longtime hospice volunteer, laments that when she worked with her children's school's Parent Teacher Association all her friends would talk to her about it for hours, but even though they all know she is a hospice volunteer even her closest friends do not ask her about her hospice work¹⁶. This reluctance to talk about hospice is bound up with a social reluctance to discuss dying, suggesting that despite ways in which we are working to change, death and dying are still taboo for many people (Becker 1973; Gorer 1955).

Hospice is also often seen as hastening death or giving up on life. Carolyn is a 72 year old Pacific Hospice patient with COPD, in a joint interview with her husband Samuel, he describes how their doctor recommended hospice to them and how it came across as the doctor giving up on Carolyn: "The doctor recommended it – her pulmonary doctor at the time. We don't use her anymore because we found that she was a little bit negative. She sort of washed her hands of her [Carolyn]. You know, there's nothing more that I can do for you – go to hospice. Not those words but you know." In this example hospice represents a negative form of demedicalization, it fills a niche for when mainstream medicine fails and there is nowhere else to turn. Here hospice is not presented as a type of medical care, it is suggested as an option to pursue when medicine itself fails.

Even among patients already admitted to hospice, the word hospice can provoke fear, especially when hospice patients living at home use it to refer to the inpatient

¹⁶ My own experiences as a hospice volunteer support this stigmatization of hospice. I told many people I was a hospice volunteer and rarely did they want to talk about it, beyond many remarks that it must be very depressing. The one exception was people who had personal experiences with family members in hospice and they were often the biggest supporters of hospice care.

hospice facility. In one instance, I observed a meeting between Gene, a 77 year old retired Navy man with metastasized prostate cancer, and his nurse, Stacey. Gene was requesting a blood transfusion, which in the past had relieved pain and renewed his energy. His nurse Stacey suggested that the Pacific Hospice inpatient center would be the easiest place to go for a transfusion, but Gene recoiled from the idea saying, “It’s the place where you go to die.” Stacey carefully explained to Gene that most people go to the inpatient care center for a few days to get symptoms under control and then return home, but Gene rebuts this by saying he had a friend he visited at the Pacific Hospice inpatient care center who died there a few days later. Stacey replies, “I can see it gives you the creeps, so let’s drop that idea for now.” Gene is a reminder that even hospice patients sometimes resist seeing themselves as dying¹⁷. Even hospice patients sometimes equate hospice with the social and psychological finality of death, not with the medical care that will improve quality of life.

This dominant meaning of hospice care as “giving up” and “choosing dying” is problematic and runs counter to the ideology of hospice care in two important ways. First the implication that hospice means a patient is “giving up” on living implies that they are rejecting patient autonomy and choice. The idea of “giving up” suggests they are ceasing to be in control in a way that runs counter to hospice ideas of patient empowerment. Second, the idea of “choosing dying” wrongly implies that death is optional or subject to human control. While much of medicine and popular culture is concerned with ways that

¹⁷ In another instance of this emotional distancing, Joyce, a 72 year old woman with Chronic Obstructive Pulmonary Disease (COPD), when asked what she believed was the goal of hospice care, replied, “I think the purpose is to keep *them* comfortable and well as long as possible.” By using the word “them”, instead of “us”, Joyce is subtly distancing herself from the identity of hospice patient.

dying can be controlled, delayed, or managed (Clarke 2005), the ideology of hospice care is to embrace a demedicalized notion that dying is natural and eventually must be accepted.

Hospice is About Living

There is another more positive meaning of hospice care, which equates it with receiving high quality medical care that will improve quality of life and may in fact extend life. This subordinate meaning conceptualizes hospice as about high quality care, which includes medical, social, psychological, and spiritual care. Hospice is not about rejecting medical care, but about reframing its goals. In this understanding hospice shifts the goal of medical care from cure to care, and from increasing quantity of life to increasing quality of life.

As some proponents of hospice care say, hospice is “about living.” Cicely Saunders herself referred to hospice’s mission as not only helping patients to die peacefully, but also helping them to live. In a quote widely used within the hospice movement Saunders said, “You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die” (1976). The perspective that hospice is about “living” focuses on the fact that hospice provides exceptional care, which often improves the entire experience of dying and sometimes extends life. From the etic perspective the idea that hospice is about living, not dying, seems confusing. Hospice patients are given a terminal prognosis and supposedly have less than six months to live. Yet as we see in the examples below, patients describe how

hospice helps them live life to the fullest until its end. The idea that hospice is about living is probably the subordinate meaning of hospice care among the general public, but one that is espoused by the majority of patients and family members who have extensive prior experience with hospice care. While many patients identified with the primary meaning of hospice care as “giving up” at the time of their referral to hospice care, at the time of our interviews most patients in my sample had changed their views on the meaning of hospice care.

Many patients told me hospice was about “helping you live”, including everything from helping with daily life activities such as bathing, to coping with the grief from current and future losses. Joyce, a 72 year old woman with Chronic Obstructive Pulmonary Disease (COPD), goes as far as to say “They [Pacific Hospice] literally, you might as well say it, they saved my life.” She explains that physically and psychologically she was in very bad shape when she started hospice, and due to the care they provided she rebounded quite a bit, and although she still has serious health problems hospice provides services that allow her to live independently.

Hospice is also about living because it focuses more on life than on death. A Pacific Hospice spiritual counselor, Marc, explains, “Because it's -- for me it's not about the death, it's not about dying, it's about living. The Hospice experience is about this process of living and having high quality life at this time and I guess this is my own spiritual experience, but I don't see this as the end of the road. I don't even think in terms of death. I think in terms of -- I like the term transitioning.” So in many ways hospice

does help people live¹⁸. In addition, research indicates many people live longer receiving hospice care than they would otherwise (Christakis and Escarce 1996; Connor, Pyenson, Fitch, Spence, and Iwasaki 2007; Mitka 2012).

Many of the patients who espoused this view of hospice as about living and caring had prior experiences with hospice care and became strong advocates of hospice care. They valued the caring, compassion, medical attention and comfort provided by hospice. They also value the pragmatic functions of hospice, providing home health aides, covering all medical expenses, and providing care at home. Judith, a 92 year old with a rare heart disease, has had multiple family members use Pacific Hospice services and is a strong advocate for hospice care.

Judith: How can I tell you or anyone else what I really think of hospice in one or two or ten or twenty or a hundred words? I have the greatest respect you could have for anything in the world for hospice. I truly believe that angels dwell there. The kindness and the caring is so phenomenal there, that it is like nothing else anywhere.

Interviewer: What is it that impresses you so much?

Judith: Their kindness. Their kindness to every patient in every situation. You will never hear a voice that is raised, everything is softly spoken kind people helping, helping all the time.

Interviewer: Was that a surprise for you in some ways?

Judith: ... My uncle died there [Pacific Hospice] and I was there with him and I had seen the tenderness that hospice has. And my Aunt also died there. So I knew hospice...So I knew hospice, the wonder of them, the patience, the kindness, the consideration.

¹⁸ A small minority of patients, family members, and even volunteers indicated that hospice was not for patients who are dying. As a researcher it is difficult to discern the difference between people who are genuinely confused about whether you need to be “dying” to be receiving hospice care and those who may be avoiding a painful subject. The incorporation of the terms “palliative medicine” and “palliative care” into dialogue about hospice appears to be related to the confusion, a point I return to in Chapter 6.

For some patients their prior negative experiences in the health care system, accentuate the value of hospice care. Steve, a 71 year old man with metastasized lung cancer, admits he had an ongoing problem with addiction to pain medications before beginning hospice care. After years of doctors failing to adequately address his pain problems, he says Pacific Hospice was able to get his pain under control within his first week of hospice care. Steve tells me, “Hospice is like mana from heaven”.

These patients and family members see the primary role of hospice as providing compassionate care, which helps them live more comfortably until they die. It is both medical prowess in areas like pain and symptom control, and the strength of relationships between patients and hospice workers that makes hospice so powerful in improving quality of life.

DISCUSSION: DOMINANT AND SUBORDINATE MEANINGS OF HOSPICE CARE

As the above examples illustrate although the dominant meaning of hospice care for new patients is one of fear and sadness, equating hospice care with “giving up”, a subordinate meaning views hospice care in a different light. While a dominant meaning of hospice interprets it as a social decision to “choose dying”, the subordinate meaning suggests hospice is “about living”. To these patients hospice was not about choosing death, they generally felt there was nothing they could do to change the course of their illness whether or not they began hospice care. Instead hospice was about choosing comfort, care, and a model of medicine that improved their lives for whatever time they

had left. In the next chapter I show how these meanings of hospice care influence pathways to hospice, particularly when and how patients choose to use hospice care.

What does this comparison of the social and medical meanings of hospice tell us about end of life decision-making? First, the social meaning of medical care can be more powerful than its medical meaning. In the case of hospice care, particularly at the time of referral, the social meaning of hospice care overwhelms any knowledge about the medical care it entails. Sometimes social meaning precedes medical meaning. Most patients in this study reported that they had very little understanding of what medical intervention hospice would provide at the time of their referral. As we shall see in the next chapter doctors contribute to this social meaning by implying that hospice is an intervention to be used when medicine fails. A stigmatized social meaning may dissuade patients from considering hospice care. Just as Conrad shows that the stigma of taking epilepsy medications leads some patients to reduce or moderate their medication use (1985), the case of hospice provides an even stronger example of how stigmatized medical interventions may be inherently problematic and avoided.

However, one of the most striking findings in this study is that social meaning of medical care is malleable and indeed changes over time. Most patients at the time they were referred to hospice held the dominant stigmatized notion of hospice as “choosing dying”. For most of the general public and for many very short term hospice patients this may be the only meaning hospice ever has, but in this study the majority of long term hospice patients came around to seeing hospice in a different light.

Many medical interventions are highly stigmatized due to their social implications. Epilepsy, mastectomies, cosmetic surgeries, chemotherapy, sexually

transmitted disease testing, are just a few examples of medical interventions that change how we view ourselves in a social context, or change how others view us. Medical interventions can increase stigma, as in the case of a chemotherapy patient who loses her hair and engenders stares in public, or can decrease stigma, as in the case of a gastric-bypass surgery patient who goes from being 350 pounds to 150 pounds. An appreciation of the social meaning of medical care will lead to a better understanding of when and why patients choose or reject medical care. While a doctor or insurer may define an intervention in terms of its medical qualities a patient or family may be and often are focused on the social need for intervention and possible social consequences.

Also interesting is the missing medical meaning of hospice care, instead hospice is seen as demedicalizing or rejecting medicine. While veteran hospice patients appreciated the medical care hospice was able to provide, along with other more holistic elements of care, at the time of referral most patients lacked an understanding of how hospice provided medical care. Instead they saw hospice as declining further medical care. Physicians and other educators could remedy this lack of knowledge by simply educating themselves and the patients about what medical (and holistic) care hospice provides. As I show in Chapter 3, this tactic can be a successful way to refer patient to hospice care, and as I show in Chapters 4 and 5 hospice care does provide a unique and highly valued form of medical care to patients.

CHAPTER 3. CHOOSING HOSPICE OR CHOOSING DYING?

In this chapter I explore the decision to begin hospice care and whether patients “choose” hospice or it is “chosen” for them. I argue that research on referral to hospice and on other medical decisions mistakenly assumes physicians are the most salient decision-makers even though in many cases patients and family members are active decision-makers. Current research on the transition to hospice overlooks the dimension of patient choice. Likewise clinical and social science literature tends to focus on how physicians can and should make medical decisions, e.g. through evidence-based medicine, or how the patient-physician relationship should operate (Cambrosio, Keating, Schlich, and Weisz 2006; Ong, de Haes, Hoos, and Lammes 1995; Quill and Brody 1996). This research often overlooks what Conrad labels the “social meaning” of medical interventions (1985).

This analysis requires a re-conceptualization of what a “medical” decision means, and what distinguishes it from a social decision. In the case of the transition to hospice care, participants view it as primarily a social decision about the process of dying and secondarily as a decision about medical intervention. I describe how this social meaning overrides the medical meaning. Both physicians and patients and families make decisions about referral to hospice based on its social meaning, downplaying its role as a provider of medical care. At the time of referral most patients, family members, and physicians shared a perception of hospice as “giving up” or “choosing dying”, likening it to a social decision about dying, not a medical strategy.

I argue here that the social meaning of medical care not only influences how patients make choices, but how physicians recommend medical care, as in the case of hospice referrals. Physician communication of the referral strongly influences whether patients and families resist or embrace hospice care. While a bird's eye view of the hospice referral process suggests physicians are primary decision-makers I show that for many patients in this study they are decisive participants either preemptively choosing hospice themselves by self-referring, or carefully evaluating whether to accept or reject a physician's referral to hospice. I present evidence that physicians, patients and family members rely upon a social meaning of hospice care when making or accepting referrals to hospice.

SOCIAL MEANING AND CHOICE

In the last chapter I argued that hospice is seen as a social decision; it is a decision to "choose dying" and often more pejoratively to "give up" on life. Meanwhile for a small subset of the population who has had prior experiences with hospice or who has educated themselves about hospice, hospice is about living; it is a way of improving and often prolonging life. It is these disparate social meanings of hospice that influence how patients and physicians perceive hospice and consequently whether they support or oppose hospice care. As Conrad illustrates in his analysis of the social meaning of epilepsy medications, social meaning strongly influences whether patients accept, reject, or modify medical treatments (1985).

The transition to hospice care was conceptualized as a good object for studying patient autonomy because hospice care is explicitly designed to be a choice that patients can opt into, an alternative to more aggressive curative medical care (Centers for Medicare and Medicaid Services 2011). Patients must be formally referred to hospice care by physicians and may accept or decline this choice. For these reasons hospice care is a treatment decision that is intrinsically more amenable to patient choice than some other medical care options, for example the “silent decisions” physicians make without eliciting patient input (Whitney and McCullough 2007).

While a fundamental premise of hospice care is that it is optional, there is a dearth of research on patient autonomy in the process of referral to hospice. The bulk of the clinical research on the question of who begins hospice care is devoted unequal access (Casey, Moscovice, Virnig, and Durham 2005; Crawley et al. 2000; Greiner, Perera, and Ahluwalia 2003), and to the issue of non-referrals or “late referrals”: when patients are referred to hospice at the very end of the dying process often living only days or weeks with hospice care (Christakis 1999; Smith et al. 2012; Teno, Casarett, Spence, and Connor 2012; Teno, Shu, Casarett, Spence, Rhodes, and Connor 2007). Most research on the process of transitioning to hospice care looks at the physician’s role in referring to hospice (Brickner et al. 2004; Christakis 1999). This research overlooks how the physician's portrayal of hospice care during the referral can sway patients either for or against it. In addition, it tends to overemphasize the decisiveness of physician referrals and downplay the patient's agency.

What is missing is an understanding of patient autonomy during the process of referral. How do patients perceive physician referrals to hospice? How, when, and why

do patients accept referrals to hospice? Do patients choose hospice because they view it as demedicalizing? When do they fear, resist, or decline hospice referrals? Finally, when and why do patients refer themselves to hospice care? The clinical literature largely presumes that physicians have control over who receives hospice care, and suggests interventions aimed at physicians. This chapter suggests physicians are a powerful force in referrals, but patients may be equally good targets of interventions since they often actively choose hospice care.

There are several reasons to believe that a patient's "choice" to pursue hospice care might be limited and constrained. Patients are often referred to hospice while they are relatively disempowered and vulnerable, either sitting in doctor's offices or lying in hospital beds. Physicians are the official gatekeepers to hospice care, but in many cases they never broach the topic of hospice with patients and never provide a referral. Christakis notes this is due to a combination of lack of emphasis on prognosis in medicine, professional and personal discomfort with discussing death, and physicians' fears about destroying patient's hope and possible effects that could have (1999). One analysis estimates physicians on average refer only 55% of terminally ill patients to hospice (Bradley et al. 2000). The general public has a low level of experience and knowledge about hospice care, precluding many patients from realizing it is an option or how to exercise that option (Gazelle 2007). Finally, hospice carries a stigma that may prevent patients from considering it.

The stigma of hospice may also discourage physicians from referring patients. Even when physicians do refer patients to hospice, if they give the impression that they are "giving up" hope for a cure, then hospice is seen as a defeat and often resisted. An

examination of the literature about patient autonomy with regards to treatment decisions suggests that in many medical decisions the very language physicians use can bias patients (Lutfey and Maynard 1998; Taylor 1988). Indeed Lutfey and Maynard's research on how oncologists break bad news includes an example of how physicians can awkwardly and abruptly bring up "hospice" instead of clearly communicating a prognosis and treatment options.

Patient choice to begin hospice care also depends upon the social implications of hospice care. Vig et al interview 30 patients and/or family members of patients who were referred to hospice, but decided not to enroll in hospice (2010). One of the primary reasons patients did not enroll was they or their family members thought they were "not ready" for hospice either because they held a misconception that hospice was only for the last hours or days of life, or because they were not psychologically ready to admit that a patient was indeed dying. Vig et al found that spouses or family members sometimes felt they would be unable to care for a patient at home (especially if the patient was doing poorly in the hospital at the time), in other cases a spouse felt "protective of the caregiver role" indicating that using hospice care would signify either an inability or lack of desire to care for a family member. Finally, there were situations in which a spouse wanted hospice care, but the patient refused. Cultural differences may also contribute to some people choosing to pursue hospice and others rejecting it (Kreling et al. 2010). As this research shows the decision to start hospice care is embedded in a social context and has a profound social meaning, it is intermingled with beliefs about dying and involves an entire family.

However, many patients do choose or at least accept their physician's referral to hospice care. In 2011 44.6% of all deaths in the United States were of individuals receiving hospice care, and 1.65 million patients received hospice care during the year (National Hospice and Palliative Care Organization 2012). All these patients (or their family members) are at least nominally "choosing" hospice care. What remains to be seen is whether they are merely acquiescing to physician recommendations or whether they are actively seeking out hospice care. Through patient illness narratives I construct a typology of referrals to hospice care and patient choice. Although a minority of patients viewed themselves as passive actors referred to hospice by physicians, a majority of patients made a deliberate choice whether to resist or accept the hospice referral. Further, another select group of patients actually self-referred to hospice care. Patients and families judged the choice to begin hospice care as a social decision and therefore felt it was within the scope of their judgment. Similarly according to patient narratives physicians often presented hospice referrals to patients not as a medical strategy, but as a social decision.

PHYSICIANS AS GATEKEEPERS

Evidence from this study suggests that how patients perceive physician referrals to hospice strongly influences their attitude toward hospice and their likelihood of accepting hospice care. As with other specialized medical services, physicians must provide a referral in order for patients to begin hospice care (Centers for Medicare and Medicaid Services 2011). Physicians and medical professionals may thwart or delay the

hospice transition by communicating the decision to start hospice in undesirable ways. Most patients in this study reported that physicians made them feel that a referral to hospice was a way of rejecting further medical care, although a few physicians worked to convince patients that hospice is a “medical” decision.

Acknowledging that physicians are gatekeepers who must give their formal seal of approval to transferring patients to hospice care is quite different than suggesting that patients passively accept the referral to hospice (or lack thereof). While a small group of patients in this study saw themselves as “chosen” for hospice by their physician, most patients described having a more active role in the referral process and actively “choosing” hospice. Some research has begun to explore how and why patients resist hospice referrals (Vig et al. 2010), but there is still an implicit assumption that patients should and can accept physician judgment about the necessity of hospice care.

I find that how patients interpret the physicians’ referral to hospice care strongly influences whether they accept or resist starting hospice care. Patients who interpreted physician referrals in a positive light were more likely to accept and begin hospice care. Patients remember these physicians educating them about what hospice care meant, and encouraging them that hospice care would improve their quality of life and may even lengthen their life. Another set of patients remembers their referral to hospice in a negative light, with an overwhelming feeling that their physicians were “abandoning” or “giving up” on them. These patients resisted and feared hospice care and in some cases delayed or refused hospice care.

Chosen for Hospice

For one group of patients physicians were not only the gatekeepers, but also the primary decision-makers in the process of transitioning to hospice. These patients did not experience the transition to hospice as a choice, instead they would characterize the decision to start hospice as being made by a physician. They were not only *referred* to hospice; hospice was *chosen* for them. In many cases these patients, although they had the right to refuse medical care, seemed to believe that hospice was their only option.

These patients tend describe the decision to start hospice as being entirely in their physicians hands, using phrases like “I was sent to hospice”. For example, Joseph an 87 year old with Lymphoma who lives with his wife in an assisted living facility explains what happened in his case, casting himself in a passive role, “He [the oncologist] put me through chemo and radiation. None of that helped. And then he signed me over to Hospice.” These patients describe the transition to hospice as something that a doctor chose for them, and like Joseph they see themselves as passive recipients of care¹⁹. Rachel, a 96 year old with a diagnosis of Debility Unspecified says her doctor referred her to hospice after she had a bad fall, “it was through my doctor that I got it, that I got hospice care. Because I didn't initiate it, she did.” Rachel describes herself as accepting her doctor’s judgment without questioning it. Another patient, Florence, a 98 year old with cardiac disease, does not remember who referred her to hospice²⁰ but she expressed

¹⁹ Many of these conversations with physicians took place months if not years before I met with patients, and I have no way of knowing what was actually said in these conversations. However, what is important is how patients remember and interpreted these events.

²⁰ Three of the 18 patients enrolled in this study could not accurately remember how they started hospice or who referred them to hospice care. In one case the patient felt her

to me that she although she accepted hospice care she feared the implication of hospice, that she was about to die. Although some of these patients may have privately feared the beginning of hospice care, they did not resist or delay the referral process.

Once they started receiving hospice care most of these patients became convinced that hospice was the right path for them. Although these patients all approved the decision to start hospice care and signed paperwork admitting them to hospice, they perceived hospice as a last resort and often feared beginning hospice care. These patients were more likely to believe hospice hastened dying and meant “giving up”. Indeed it is likely that many patients who are referred to hospice decline hospice care due to their fears that hospice means *choosing* dying. The majority of patients in this study were referred to hospice by their physicians, however only a few passively accepted that decision (as in the cases described above). In most cases patients recount a dialogue with their physicians about if and when they should be referred to hospice. In the cases illustrated below we see how physicians and patients discuss and negotiate the topic of hospice care. In some cases physicians must “sell” the idea of hospice to patients who resist it, in other cases physicians make patients feel abandoned during the referral process complicating and sometimes delaying their acceptance of hospice care.

Negative Physician Referrals: Abandoning Dying Patients

Often the patients who most strongly resisted or delayed beginning hospice care were those whose physicians left them feeling abandoned. Physicians who had a negative

daughters made the decision, in another a patient reported someone at a hospital decided she should be discharged to hospice.

referral style couched the referral using language like, “there is nothing else we can do for you”. These referrals made patients feel like hospice represented a form of abandonment by physicians who either could not or would not help them to get better. In these cases patients remember doctors describing hospice in such a way that they equated it with giving up medical care and choosing to die. These negative referrals framed the hospice decision as one with strong social meaning and included very little explanation of the medical care hospice would provide.

Cliff is a good example of a patient who experienced a negative hospice referral as a form of abandonment, and he strongly resisted beginning hospice care. Cliff is an 89 year old with a diagnosis of ALS (Amyotrophic Lateral Sclerosis), also known as Lou Gehrig’s disease. He has severe shortness of breath and muscle weakness, lives alone in his family home, and has a hired caregiver²¹, Lucia, but no remaining family nearby. When he describes how he ended up at hospice, it was due to a lack of other choices.

Well when I figured I had Lou Gehrig’s, and the two main doctors at Kaiser, they both of them said they could not do anything for it. So they examined me again. So I quit them [Kaiser] and then joined the VA [Veteran’s Administration]... And they gave me every single test you could think of, trying to prove that I did not have it. And they proved that I did [have ALS]. I don’t quite know who referred to hospice but I think it was the VA.

²¹ When I refer to a “hired caregiver” I am referring to a home health aide, sometimes hired through an agency or sometimes hired independently. In this study I encountered hired caregivers who assisted patients with a spectrum of needs for varying times, ranging from a few hours a week to 24 hours a day 7 days a week. I use the term “hired caregiver” for two reasons, to distinguish these privately paid home health aides from the hospice home health aides who are employed by Pacific Hospice and paid via Medicare. Also I wish to reinforce that these aides are primarily caregivers and often perform many of the same functions as family member caregivers.

Being given this feared diagnosis and prognosis and being told by his doctors that they could do nothing to help him was terribly depressing to Cliff. With no family to rely upon, he was very nearly forced into a nursing home, a fate he considered to be worse than death. His hired caregiver, Lucia, who was with him when he was diagnosed, said that when he was told he might have to go to a nursing home his reply was, “I prefer to kill myself. I have a gun²².” Although he was referred to hospice by his health care provider he did not initially accept the idea of hospice and it took months of reflection and hard work by his caregiver, Lucia, to convince him to try hospice care.

Lucia recounts doing research online about hospice and gradually cajoling Cliff into trying it by promising him he could quit after a month if he did not like it. Lucia recalls, “I start to checking the computer. How hospice works. Okay. I start reading and reading. I say, okay. Maybe they could help some, you know, because he doesn’t like to go out and have, even if I want to take him outside to get some sunlight²³.” Lucia was able to learn one key thing that eventually attracted Cliff to hospice; he is a very social person who appreciates visitors and conversations, but does not like leaving the house due to his medical issues. Hospice would allow him to stay at home and have visitors come to see him when and where it was convenient for him. Cliff eventually accepted the referral because hospice care offered him a viable alternative to a nursing home, allowing him to remain at home with help in the form of the home health aide, nurse, social

²² Indeed Cliff did have a gun, which he brought out to show me on two separate occasions while I visited with him. He worked part time as a gunsmith throughout his life and made beautiful old-fashioned pistols. The gun made his caregiver Lucia uneasy, but Cliff told me he wanted to have something in his home for self-defense.

²³ Lucia, like some of the other hired caregivers I interviewed was not a native English speaker and sometimes had trouble expressing ideas in English, but in interviews I would ask her to clarify anything that was ambiguous.

worker, spiritual counselor, and volunteers coming to meet with him on his terms, in his home. When I met with Cliff he had been on hospice for over a year and was very happy with the care he was receiving and his ability to remain at home.

Cliff demonstrates the complexity of agency during the process of referral to hospice. Although Cliff ultimately accepted his physician's referral to hospice, he first resisted hospice care, and his hired caregiver played a pivotal role. Ultimately Cliff made his decision to accept the hospice referral for largely social reasons, including his desire to stay in his family home and his desire to have more visitors. Cliff did not see hospice as a medical intervention or as something that was likely to change the course of his disease, instead it was a social intervention.

Many patients remember their physician's referral to hospice as tantamount to a "death sentence" and their first reaction is to recoil from the idea. Several patients refused hospice care at the time of referral only to come around to the idea eventually. Joyce, a 72 year old with Chronic Obstructive Pulmonary Disease (COPD), was referred to hospice by her pulmonologist. Her husband, Tom, describes what happened 4 years ago when his wife was referred, and as he speaks his eyes well up with tears.

Tom: To make a long story short they did a bunch of tests and the bottom line was that the doctor brought us both in and he says "well...", she'd had some x-rays and stuff, well I forget if it was an MRI or x-rays or whatever it was. The doctor brought us in and said "well, it's COPD. It's a terminal disease, there's nothing we can do about it."

Interviewer: So he said there's nothing you can do about it?

Tom: Well he said there was no cure. Or she [the doctor], she said there was no cure. And she offered at that point to contact hospice. And I just went to tears, and uh. We talked it over. We declined at that moment because we thought hospice was someplace you go and die.

Although we can not know exactly what words Joyce's pulmonologist used, it is clear the way she revealed that Joyce had a terminal disease and then abruptly recommended hospice left both Joyce and Tom feeling desolate and helpless. In this case and many others when the physician says, "there's nothing we can do about it," it makes patients feel abandoned or rejected.

Many of the patients in this study initially associated hospice with having only weeks or days left to live. Tom went on to explain that they had friends and family members that received hospice care, but that they all died very quickly. They interpreted the decision to start hospice care as a social choice about admitting impending death, and they had little understanding of what type of medical care hospice provided. Joyce and her husband Tom initially declined hospice and only accepted hospice care after months had passed and her health had further declined. Tom describes why they waited to accept hospice care, likening it to a "death sentence" which they were not ready to accept.

We both declined initially. We didn't really understand the program, like most people don't. And we said no because it was like we would allow the death threat, I mean the death sentence. We just didn't understand you know how much they do for you. And all the help they give. And so we waited, I think at least three or four months, well it was quite a while, before we finally changed our minds.

Cliff, and Joyce are like the majority of patients who saw hospice as a last resort. They accepted hospice care with some fear and trepidation, but after beginning hospice care quickly began to appreciate its value and felt they were getting the best possible medical care. They began with the dominant social meaning of hospice, which treats it as "choosing dying", but over time adopted the subordinate meaning, focusing on how hospice helps them to live. These patients and their family members, like most study

participants I interviewed, were enthusiastic supporters of hospice care with a deep appreciation for the unique qualities of hospice care.

Not all patients who felt abandoned during the referral process came around to be enthusiastic about hospice. Gene, a 77 year old Navy veteran with metastasized prostate cancer, had a lingering ambivalence toward hospice. Like many others he resisted the idea of hospice and was afraid of its social meaning: that he was dying. He tells me that he still hopes that any day his oncologist might call and tell him that there is some new treatment to try or some miracle cure. If that happened, he says he would stop hospice in a heartbeat. But given his situation he appreciates the practical benefit of receiving care at home and having a team of people managing his medical care. Gene describes how he was referred to hospice.

Well I remember the time when the doctor told me, he said, "I'm going to ask hospice to come". And I objected to that, very much so, because my vision of hospice was - well you're dying and you'll be dead soon and hospice is there just to see that you get, that you face death as calm as possible. And I objected to that because that was my sole knowledge of hospice. And then he said no it's palliative, and then I said, well let's explain that a little more. And he did, and then I saw that.

As Gene remembers it, his doctor presented hospice as a decision that he had already made without Gene's input. Gene was understandably indignant, but after his doctor provided some further education about hospice he decided to accept it. However, despite his rational understanding of why hospice would be a good choice, he retains a feeling that his doctor abandoned him. Recalling when his doctor suggested hospice Gene says, still indignant, "To me he was saying, we're going to let you die. That is exactly what he was saying, in my mind. Because the only time I ever heard of hospice someone

was dying.” For these patients hospice provokes strong and understandable fears and for some a feeling of betrayal that doctors are giving up on them. These patients do not view hospice as a medical decision, but as a social decision to opt out of medical care. The idea of betrayal by medicine and doctors is linked to a negative type of demedicalization: abandonment by physicians and mainstream medicine.

Many patients experience the referral to hospice as this negative form of demedicalization. This perspective sees hospice as an inferior alternative to more potent curative medicine. Under this conceptualization hospice means being forced to reject attempts to cure and heal. Charlie is an 86 year old with a diagnosis of Debility Unspecified and history of heart disease. He is one of the only patients I met who voiced substantial complaints about hospice²⁴. He regrets that he cannot receive both hospice care and more aggressive curative medical treatments simultaneously (a restriction placed by Medicare to control costs). As Charlie emphasizes, “... because to be perfectly honest with you, I want to keep going. I don't want to have a minor heart attack and give me a couple pills. I'd like to have something done about it.” However, the utilitarian benefits of hospice led him to accept hospice care. Charlie accepted hospice care because he was exhausted from his endless medical appointments, as he describes it: “Honey, I was on the road every other day seeing a doctor, seeing a lab, seeing X-rays, seeing this and seeing that.” Hospice has a practical benefit; it brings professional medicine into the

²⁴ While Charlie was ambivalent about hospice for himself he recognized that the value of hospice changes depending on who is receiving care. Charlie lives in a condo with his wife who has advanced dementia, is bedbound, and is also receiving Pacific Hospice care. He viewed hospice as a godsend in her case as it allows her to stay at home with him and receive high quality care. Because there are no cures or treatments for dementia he considers hospice to the best medical care for his wife.

convenience of the patient's home. Yet Charlie feels that accepting hospice care means rejecting and being rejected by mainstream medical care, and perhaps shortening his life. He would prefer to continue to see his cardiologist and be eligible for surgeries and aggressive treatments. Because he had to decline curative treatment to begin hospice care he sees mainstream medicine as abandoning him when he began hospice. This form of demedicalization does not free patients from objectification instead it is experienced as reducing patient choice.

In the cases above I argue that physicians play a pivotal role in whether patients will welcome or fear hospice care. These examples show how most patients remember physicians' referrals to hospice as having a dominant social meaning, implying that they were choosing to die, and there was little explanation of the medical benefits or strategy of hospice care. I show that in some cases patients did not feel they had a "choice" whether to begin hospice care, but in most cases patients took an active part in deciding whether or not to accept referrals to hospice. In most cases physician referrals were seen as negative, emphasizing that the patient was dying and giving patients the impression that they were "giving up" on them or "abandoning them".

Positive Physician Referrals: Choosing the Best Medical Care

A small number of patients in this study had physicians who worked hard to provide a positive referral to hospice, educating patients about why hospice was advantageous to them. In these cases physicians realized patients feared hospice so they worked hard to make the referral to hospice be seen as positive and beneficial to patients.

These physicians achieved this redefinition by convincing hospice patients that hospice is a “medical” decision and not an indication of an attitude toward dying.

In these instances we see how the line between a social decision and a medical decision is flexible and can be manipulated by a physician. Rose, a 90 year old who lives in her family home with one of her sons, spent decades living with COPD and getting progressively worse, here she describes what happened when her pulmonologist suggested hospice.

I told him that I'm not ready to die yet. And he says no, he said, of course you're not ready to die. I want you to stay that way. And that's [hospice is] the best way to be assured that you won't be ready to die anytime soon. And that's how come I went to hospice, and it's three years ago the end of July... He says you don't understand. I am sending you there. He said that's the place for you to get the best care of all and he was right because I think they come to me, Shirley [home health aide] and the lady who -- they're all -- excellent –

Rose's initial reaction to the idea of hospice was that it meant her doctor felt she was ready to die and that going there would speed her dying. She admits she reacted with fear and resisted the idea of hospice. However, Rose's physician spent some time educating her about hospice and the services that would be available to her, and she eventually accepted the idea of hospice care as something that might help her lead a more comfortable and longer life. Buttressing this point of view is a growing body of research which shows that for people with many types of illnesses receiving hospice or Palliative Care actually leads to them to live as long or even longer than a comparable populations without hospice care (Christakis and Escarce 1996; Connor et al. 2007; Mitka 2012). Rose accepted the referral to hospice and when I met with her she had been receiving hospice care for four years.

In other cases physicians stressed specific medical care aspects of hospice that they knew would be appealing to patients. Patients told me that physicians assured them that they would be able to stay out of hospitals, emergency rooms, and doctor's offices; that they would get high quality medical care at home; and that they would have the best expertise in pain relief. Many of these patients had no option for aggressive medical treatment to cure their disease. In this case hospice offers a utilitarian advantage and a new model of care. Instead of making repeated visits to hospitals when their health worsens, a problem Kaufman labeled the “revolving door pathway” in her study of hospital Intensive Care Units (2005), hospice patients receive medical attention in their homes. In these cases hospice is seen as ameliorating problems with the current medical care system and providing a better form of medical care.

UNEXPECTED AGENCY: PROACTIVE PATIENTS AND FAMILY MEMBERS

While the above cases concern the majority of patients who enrolled in hospice following physician referrals, a substantial minority of patients in this study were proactive in obtaining hospice care by educating themselves and self-referring. In this section I show how patients and their family members have a level of agency previously unexamined in the process of transitioning to hospice care. These patients and family members chose hospice for themselves, requesting referrals from physicians whose role seemed to be simply to sign off on the referral. These patients saw hospice as their *choice*, and they tended to emphasize hospice’s positive demedicalizing qualities.

The most striking finding of this study with regards to patient choice is that some patients and their family members proactively seek out hospice care before their physicians suggest it. Their reasons are telling; they focus on the desire to avoid intrusive hospital medical care and the ability to remain at home. These patients and their family members see hospice as a social decision, one that is less medicalizing than the alternative of dying in nursing homes or hospitals. They see the positive demedicalizing influence that hospice can provide.

Prior experience with hospice or knowledge about hospice played a large role in influencing these patients. Patients with more favorable impressions of hospice care, who espoused the subordinate meaning of hospice as “about living”, were quicker to choose hospice care, often self-referring instead of waiting for a physician to suggest hospice. The patients who self-referred to hospice were more likely to accept the idea that they were near death and to appreciate the holistic and demedicalizing qualities of hospice care. While patients who were referred by their physicians tended to focus on the social meaning of hospice as “choosing dying”, patients who self referred saw themselves as “choosing hospice” which was both a social decision and a medical decision.

Hospice as Demedicalizing

For some patients hospice represents a way of opting out of mainstream medical care when they no longer want aggressive treatment. These patients were tired of intrusive medical treatments and welcomed a more demedicalized approach to dying. Some patients opted into hospice care right after they were diagnosed, others went

through many rounds of surgeries, chemotherapy and radiation, or other treatments before they chose hospice. What unites this group is that they did opt out of aggressive treatment, even when doctors were still recommending further aggressive treatments. The majority of these patients actually self-referred to hospice, they requested hospice instead of waiting for a doctor to refer them to it. As a group they also share knowledge about hospice, either gained from personal experiences with hospice care or from educating themselves.

Just as patients have preconceived notions about what hospice means, so too they have preconceived ideas about what their illness means and what the future holds for them. In some cases their illnesses progressed slowly, in others they declined suddenly. The patients' illness narratives, including their assessment of the timing of their illness in their life course and their past experiences with death and medical care led some patients to see hospice as a positive choice, a way of opting out of medical care they did not want. For patients in this group physicians were only nominally "referring" patients to hospice care. These patients sought out hospice care and either self-referred, requesting a referral to hospice before a physician brought it up, or made independent decisions to start hospice care.

Reasons for opting out are various. For Judith a 92 year old with a rare heart disease called Idiopathic Hypertrophic Subaortic Stenosis (IHSS) it was her reluctance to undergo surgery at an advanced age, which she judged held at least as much risk as her actual diagnosis. Judith describes getting the diagnosis of IHSS and going to two doctors for advice.

So I went first to one [doctor], and he thought I needed open-heart surgery. And then I went to Doctor Rosenfeld, and he said “honey you got to have open heart surgery to take care of this”. And I was 85 years old. I said, you’ll find out that I’m quite different, I said, “I’m not going to do that.” I said, “I’m 85 years old and I have seen many of my friends go in for surgery and they never come out the same – weaker, more frightened, more fragile. I said, I’m not going to do that, so please tell me how long I have to live if I don’t do surgery, which might kill me anyway. And I’m not afraid of that, it’s just that I don’t want to be exposed to it. And he said, honey not more than 6 months. And so I said to Dr. Jacobs, what do you think? I’m refusing the surgery, how long do you think I have to live. He said, honey not more than six months. And so I said, ok. So then I came home and I cut up all of my charge accounts. I took out the little cards, I cut up all the credit cards except one, I kept one.

Judith is representative of a group of patients who made a calculated decision that the risks of aggressive treatment outweigh the benefits. She sees hospice as demedicalizing, but also as more likely to preserve her health than open-heart surgery. Expecting to live only six months she made an effort to pay off her debts before her death. Judith had been a caregiver to a brother with Alzheimer’s who eventually used Pacific Hospice services and she already had a deep appreciation for hospice care. She called Pacific Hospice herself and asked to be admitted, what is known as a self-referral. For Judith hospice was not representative of “giving up” or “choosing dying”, she felt surgery itself would be more injurious to her health than hospice care. However, Judith did have an unusual perspective on dying, she stressed many times in our interviews that she was not afraid to die and that she even welcomed it as her next adventure. Her personal experience with hospice and knowledge about how it could help her also guided her to choose hospice when many others might have selected surgery. Her medical

prognosis proved to be incorrect²⁵ and Judith lived for over 6 years after beginning hospice care.

Other patients opt out of conventional care because they judge that it is futile. These patients realize they are deteriorating and that medical science is unable to change that. They choose to spend the end of their life in a way that is comfortable for them instead of occupying what feels like all their time and energy on medical care. They do not see choosing hospice as opting out of medical care in general, just a specific form of very intense and typically hospital based medical care. Jerry, an 80 year old former golf professional with COPD, emphysema and another rare lung disease, is an example of this type of opting out as he described the day he “fired” his pulmonologist. He describes feeling like a “guinea pig” with regards to all the tests and treatments his doctors had tried with him. Below he describes a doctor’s appointment he had, and how upset he was when he waited over an hour after being shown to an examination room only to find out later his doctor had been late because he was at his own dentist appointment.

Jerry: You know, the same old thing. Well question you this, question you that or this or that. I want you to take another breathing test. I want to put you on -- I says I have enough trouble now. I'm not going to get any better. What do I have to go through all this stuff for?

Interviewer: Uh-huh.

Jerry: I said it's a matter of you making more money and me being more miserable.

²⁵ As many hospice workers told me medical prognoses are often incorrect, they are after all probabilities. Usually with the aid of statistical software physicians can make a prognosis that 50% or more of patients with the given diagnosis and characteristics will die within six months. However, 50% of patients will live longer. In some cases, as with Judith, they may be in the small minority who live much longer than predicted. Jennings, Beth. 2006. "The politics of end-of-life decision-making: computerised decision-support tools, physicians' jurisdiction and morality." *Sociology of Health and Illness* 28:350-375.

Interviewer: Yeah, yeah.

Deborah: Of course that went over like a lead balloon.

Interviewer: You said that to the doctor's face?

Jerry: Well you know it's the truth.

Interviewer: Something like that? Yeah.

Jerry: You know they're pushing things in there, take a sample, do this and sticking things in my bones and taking samples of this. I said this is not necessary. I mean I've got a disease that's progressive. It's getting worse.

Like others Jerry describes the burden of undergoing conventional medical treatment and how that factored into his decision. As with other patients with lung problems and many patients with advanced illnesses, even walking from his kitchen to his living room can cause Jerry shortness of breath and exhaustion. He elaborated on how difficult it was to physically travel to doctor's appointments, to face walking long distances across hospital or medical office complexes, to wait indefinitely in waiting rooms, to be subjected to many uncomfortable tests and treatments with no sign of improvement, and sometimes to be treated disrespectfully as in the example of the doctor who scheduled his dentist appointment at the same time as Jerry's doctor appointment. These patients do not want to reject all medical care they simply want less medical intervention. Hospice represents a middle way since it is more demedicalizing than mainstream medical care, but still offers medical monitoring and management.

Like most of the other patients who self-referred, Jerry did not choose hospice immediately after his diagnosis, he underwent years of conventional medical care following the advice of specialists. At one point his primary care physician told him

hospice would be good for him, and when he became frustrated with the care his pulmonologist was providing, he decided to pursue hospice care. Like Judith, Jerry had personal experiences with hospice care; his mother-in-law had received care from Pacific Hospice years before. It was this knowledge and appreciation of hospice that guided his decision. It is also critical to point out that for both Judith and Jerry, this was not merely a decision about which medical care to pursue, it was a decision about dying. It was a decision that acknowledged they were close to dying, and that showed they were trying to maximize their comfort during the time they had left.

Getting off the Roller Coaster

Although some patients carefully calculated the costs and benefits of continuing aggressive medical care, others experienced a more emotional reaction to the idea of subjecting oneself to the physical and mental turmoil caused by aggressive treatments. Jerry's wife Deborah describes her mother's experience choosing hospice over further oncology care. Deborah's mother had breast cancer that was successfully treated by mastectomy, then years later she found a lump on her neck which turned out to be cancerous. Deborah describes what happened next.

So we went to the doctors I knew at [the clinic] because she was in the same program and so, you know, the one doctor said to me -- I said -- a female doctor I was very impressed with her work and her patients. I was privy to seeing a lot of that working, and so I took mom to her first and I asked her later, the doctor later, I said if it was your mother what would you do? And she said leave it alone. And I didn't say anything because we did have another appointment with a surgeon that I thought that maybe he, you know, would check things out, the cancer and everything, and he told her -- he said well now this is what we can do, but there's no guarantees. And she says "no", she said, "you had me once, you're not going to get me

twice.” And she made up her mind that that's -- she was leaving it alone. Her choice.

As Deborah recounts, her mother did not even consider going through another round of cancer surgeries and treatment, even though earlier in her life cancer treatment was successful. Deborah then describes that her mother flew to Texas and spent three months visiting with her other daughter. Then one day she woke up and said she was “sick” and needed to go home. Deborah called Pacific Hospice to refer her mother and she started hospice care a few days after returning home. This story demonstrates the complexity of the decision to start hospice. First it is not always the right choice, timing matters. Earlier in her life Deborah's mother was willing to pursue more aggressive treatments for her breast cancer, the analysis changed for her second bout with cancer. Second, physician opinions and suggestions matter, but they are not necessarily decisive. It is also noteworthy that Deborah did not ask for statistics on the probability her mother would survive cancer treatment, she simply asked the physician what she would do if it was her own mother in question. She was relying on the physician's intuition and emotional judgment as much as her scientific expertise.

For Deborah's mother this is an emotional decision, she had been through a difficult cancer treatment experience earlier in her life. Her phrase, “you had me once, you're not going to get me twice,” indicates a set of attitudes toward cancer treatment during which she felt the doctors controlled what happened to her the first time around, and this time she wants to be in charge. Many patients who opted into hospice care saw it as a reprieve from the grueling experience of treatment for their illness. These patients tended to have had extensive experiences with aggressive medical care and they were

often cancer patients who had undergone months or years of treatments that were exhausting and debilitating. Like Jerry and Judith, Deborah's mother wanted to avoid over-treatment, which has its own physical and mental costs.

While some patients like Judith and Deborah's mother, chose hospice after little or no curative medical treatment, others reached that decision at a later point after months or even years of aggressive treatments. Henri, a 77 year old a retired physician, was diagnosed with colon cancer and a year after what he thought was successful surgery it was found that the cancer had metastasized to his liver. As he recounts Henri then went through successive rounds of radiation and chemotherapy before he decided he had had enough.

So then I embarked on another course of chemotherapy with a different agent, and that one I did not tolerate so well. And that finished February this year. And at that point it was clear that it was not effective, I mean it had not even kept it in check. So at that point, you know, no more treatment. There was another option of some direct injection of some radioactive beads into the liver, because that is the only place I have the disease. And it consisted of a bunch of invasive procedures to get it done, the chances of it having a favorable outcome were 30%, which isn't a bad percentage, but at that point I said you know I've had enough of a roller coaster ride, thinking that it is going to do something. So I chose not to do that. So since February basically I have not had any treatment for it. And that's where I am.

Henri's roller coaster ride was both physical and emotional and he saw hospice as a way of escaping that turbulence. Henri's professional expertise with medicine and personal familiarity with the benefits of hospice (his mother had received Pacific Hospice care year ago while living with he and his wife), led him to choose hospice when he was ready to stop other treatments. Many patients like Henri, particularly cancer patients, stressed the physical and mental turmoil caused by rounds of treatments.

Another patient with cancer, Steve a 71 year old with metastasized lung cancer also viewed the decision to start hospice as getting off a roller coaster. Steve summarizes his experience with chemotherapy: "I felt like a big piece of meat thrown on the clothesline." When asked if he was in pain, he said, "It's not exactly pain, pain is a definite thing, this was a state of being where you feel like merde, you would rather be dead". He believes his oncologist would have kept treating him until he died, and said that, "the oncologist wants to keep going, because if he stops it's an admission of defeat." It was Steve's primary care doctor and a neighborhood pharmacist who was also a hospice volunteer who educated him about hospice. Eventually Steve told the oncologist he wanted to stop treatment and begin hospice care. An important factor for Steve was hospice's expertise in pain management since he had a history of pain problems and addiction to painkillers. Indeed, Pacific Hospice made an enormous difference in Steve's quality of life, after beginning hospice care he told me his pain became controlled for the first time in years. For Jerry, Henri, and Steve hospice did not start out as a first choice, but after a long time dealing with very aggressive and debilitating treatments and the associated pain and discomfort they chose hospice. These patients were knowledgeable about hospice's *medical* rather than *social* meaning and chose hospice based on the medical care it could provide.

Staying at Home, Staying out of the Hospital

Many of the patients who chose hospice care were driven by a strong desire to remain at home through their illness and the dying process, and sometimes an equally

strong fear of going to hospitals or nursing homes. These preferences are both social and medical decisions. Patients may genuinely dislike the idea of intrusive medical treatment they receive in hospitals, but may be equally motivated by the desire to remain in a beloved family home, near family, and familiar caregivers. Dottie is an example of someone who has had a strong fear of ending up in a nursing home since the time she watched her husband die of Alzheimer's in a nursing home. Her son and primary caregiver, Doug, described to me how his mother preemptively chose hospice care. Dottie at 94 years old unexpectedly woke up one day and could not walk; she had lost most of her mobility. The doctors suspected strokes, but there was nothing that could be done to reverse her condition. Doug explains that his mother was already familiar with Pacific Hospice since she had friends who received care with them. Doug explains that it was his mother who called hospice to refer herself, "... So she called Sally [a hospice contact] and I mean bingo, I mean it happened right now, and then, you know, the bed and the wheelchair and, you know, all this stuff and people and nurse." Dottie's own prior knowledge of hospice in addition to her recognition that no aggressive treatment was available (or desirable) led her to choose hospice before any physicians recommended it. Hospice care allows Dottie to stay out of a feared medical institution, the nursing home, and allows her to remain at home.

In some cases it is family members or hired caregivers who are instrumental in obtaining a referral for hospice care. June is a widowed 89 year old with a diagnosis of

Debility Unspecified who lives in a board and care facility²⁶. In her case one of her daughters worked for years as an office manager in an oncology office and was the one to recommend June begin hospice care, to educate her about hospice, and to pursue a referral.

In another example, a daughter again is instrumental in navigating and advocating for her parent. Colleen, interviewed in this study describes how her mother had a fear of dying in a hospital and a particular fear of being intubated, long before she was seriously ill. Colleen's mother lived with her at this time (and until her death), so Colleen made it a point to learn about the various options for care at the end of life. She read a lot about hospice online and then decided to volunteer for Pacific Hospice to learn even more in preparation for what might be required with her mother. It was this research that led Colleen and her mother to request Pacific Hospice care, which allowed her Colleen's mother to have the peaceful and calm death at home that she wanted.

Below Colleen describes her mother's preferences and some of the resistance she faced from within the family after her mother had a serious stroke.

She wanted to stay home. She didn't want to die covered with tubes, and I'm sure you've heard that from many people. And it's amazingly hard to accomplish that unless you go with hospice. You know even when she filled out all those forms and stuff like that, the temptation to go to the hospital is very strong because you think that they can do something for her. My sister and her daughter -- they went along with hospice but weren't as -- I don't want to say enthusiastic, but they weren't as on-board about it as I were. My niece works at [a hospital], so she's more plugged into the whole, you know, maybe they can do something for Grandma.

²⁶ Board and care homes, sometimes called Residential Care Facilities, are private residential homes akin to “group homes” for elderly residents. They generally have 6 patients per home and staff to provide assistance with all activities of daily living.

Moreover, when her mother's health worsened Colleen took the initiative to try to ensure her mother would be referred to hospice, something that would almost certainly not have happened without her efforts. As Colleen explains her mother never discussed the severity of her health problems with her doctor, and the doctor may not have referred to hospice even if she had.

I took Mom to see her doctor, and Mom, like a lot of people of her generation, she was in her 90's -- when she goes to see the doctor, no matter how much effort it takes she will dress nicely. And her default answer to the doctor whenever he asks her "Well how are you?" is "I'm fine." You know, in other words we'll put on this act when actually that's not the point of being there, right? But that is what she'll do, and I remember this visit to the doctor and just watching her go through this, and I knew that he was going to probably write down something like "pretty much no change, she's fine", and we went home. And I wrote a letter to him in which I explained this to him and said -- and then gave him basically a precise description of what her typical day was like, and to what extent she needed help, all of the things which he could not know because in today's world even a good doctor doesn't have the time to sit down and talk to her and pry it out of her. It just doesn't happen anymore. So I said so I'm thinking that I'd like to call hospice, but you need two things to become a hospice patient. One is a diagnosis of a fatal disease, and the second -- or at least what would you call it, failure to thrive, that kind of thing; and you need the doctor's okay, his support so to speak. So I wrote him the letter and he said yeah, okay, let's see about hospice and what they have to say.

Colleen did several things that were crucial to her mother receiving hospice care; she educated both herself and her mother about hospice, she attended her mother's doctor's appointment, and she wrote a letter to her mother's doctor advocating for a referral to hospice²⁷.

²⁷ With regards to the cultural ideal of a good death, this is a nice example of how it is not by any means the default, but instead it is something that requires active effort by both patients and caregivers.

Caregivers and family members often advocate for a patient to begin hospice care as the means to one important end: allowing them to remain at home. One of the spiritual counselors working for hospice, Barbara, described how her experience taking a class on death and dying while in seminary led her to refer both her elderly grandmothers to hospice soon after, and subsequently led her to her current career as a hospice spiritual counselor.

In seminary, I took an elective called Death and Dying in Pastoral Care. I didn't really see it as a career move, as much as I had these two elderly grandmothers that were big in my life and I took that class. It was actually taught by a Pacific Hospice Chaplain. She brought in social workers and nurses. So, that was kind of my experience. And actually, we weren't really referred to hospice in either case, we self-referred. So, I think there can be some development and some education about referrals because if I hadn't had that experience, not to say we would've never gotten hospice, but we might not have gotten it when we did. The one grandmother actually became hospitalized and the doctor actually told me on the phone, she's not going to make it out of the hospital and I said, you know, she doesn't want to be here, can she go home on hospice? And I actually feel like I got a little bit of push back from her on that but I said, no we want her to go home with hospice.

In both the instance of Colleen's mother and Barbara's grandmothers not only did patient preferences play an important role in determining referral to hospice, but all three women discussed specifically did not want to die in a hospital. It was the fact that their daughters and granddaughters educated themselves about end-of-life issues and options and actively pursued a hospice referral that allowed these patients to receive hospice care and to die at home as they wished.

Many choose hospice care because of another utilitarian benefits: through Medicare funding hospice is one of the only services that provides long term home health aides at no extra cost. This financial benefit plays a role for the majority of patients who

cannot afford to privately pay for home health aides. Many participants explained to me that it was this desire to have someone (the hospice home health aide) come help bathe them two or three times a week that was a deciding factor in beginning hospice care. Isabel, a hired caregiver for one of the hospice patients participating in this study was simultaneously helping her mother provide care at home for her grandmother (when she came home from her day job). Isabel explains that due to her grandmother's weight and difficulty breathing having a home health aide to help move her and bathe her very important.

Well my mom was taking care of her, but my mother was getting tired, because my grandma was you know a big lady, so you know she asked for help because she can't do it no more, because my grandma can't even walk, she was big, and she had lung cancer, so she get out of breath so quick and so bad like she could walk from here to there and she's out of breath... So my mom and her sister, you know get together and they would ask for help you know somebody could come and help with the showers.

Hospice has three features that are appealing to many patients and families. It allows patients to stay out of hospitals and nursing homes, allows them to remain at home, and pays for home health aides to provide in-home care. Charlie, who as I discussed earlier felt ambivalent about his own hospice care, has a wife with dementia who is also a Pacific Hospice patient and he thinks it is a wonderful choice for her. As Charlie says: "We all know what the situation is. It's just a matter of time. It's a matter of keeping her comfortable and pain-free and clean." For patients like Charlie's wife who never had the prospect of a cure, hospice allows them to receive good medical care at home and to avoid two feared institutions hospitals and nursing homes.

These patients who proactively chose hospice are set apart in several ways made obvious in these narratives. They or their family members either had prior knowledge or experience with hospice, or they worked to educate themselves about various options including hospice. These patients were not passively accepting the advice of doctors. They were proactive, steering their course through the health care system. These particular patients all highly valued dying at home for both social and medical reasons, and hospice care enabled them to die at home. Furthermore hospice helps patients avoid two of things most commonly feared: dying alone in a hospital or nursing home and dying hooked up to machines. In this sense home hospice care is an educated and deliberate choice for some patients and their caregivers intent on ensuring their preferences for how they want to die are met. These preferences are inherently demedicalizing, they want less medical intervention and they want to be in a family setting not a medical facility.

In these examples choosing hospice is not a question of choosing to die, it is a question of choosing how to live one's remaining days. These patients are often strategically choosing what they think will allow them a maximum time of comfort and low stress at the end of their life. Some are also carefully choosing what they think will allow them to survive longer, either because of the risk associated with surgeries and other treatments, or because they realize that doctors can not calculate how damaging certain treatments are to their bodies and holistic health. However, the decision to pursue hospice care for these patients also represents a different attitude toward dying. These patients as a group speak more openly about dying. They are not necessarily more ready

to die (although some say that they are), but they seem to be more at peace with the idea of their deaths occurring soon.

THE SOCIAL CONTEXT: WHY SOME PATIENTS EMBRACE AND SOME RESIST HOSPICE

The above descriptions focus on two social determinants of the choice to start hospice care. Physician-patient interactions and patients' evaluation of the social meaning of hospice care lead them to accept or resist hospice care. However, there are other subtle and compelling reasons that some patients embrace hospice care and others resist it. I will use the example of one hospice patient, Dana, to explore the social motivations and social consequences of the decision to start hospice care – what I call the social context of decisions.

Dana is a patient who came to hospice four years after her original diagnosis of lung cancer. Dana is 79 years old, divorced, and lives alone in a mobile home, although one of her daughters comes to assist her nearly every day. Dana's oncologist referred her to hospice after he discovered that her cancer had returned after a remission of several years. Dana says, "...he just turned me over to hospice then and there and said they'll contact me next week and that was that. He sent me home." The way Dana tells the story she and her family passively accepted the doctor's recommendation without any protest or doubts.

Dana: He said come on over to hospice, you've got up six months to live and that's it.

Interviewer: The doctor said that?

Dana: Uh-huh. It's inoperable and it's terminal and he said why go

through any more surgeries and tests and stuff? So we just said okay, we'll just ride it out and when it's my time it's my time.

Dana's story taken at surface value is the story of a patient who could have easily interpreted her physician's referral as "abandonment". Yet Dana did not fear or resist the transfer to hospice care. Although it was Dana's doctor who selected hospice as the best choice for her, Dana did not passively accept this pronouncement. If our interview had ended following this description I might have guessed that she felt abandoned and that her physician had given up on her, but Dana went on to describe to me the prolonged period of discomfort and suffering she experienced, the fatalism she felt about her cancer, and her readiness to die. Dana had been through years of cancer treatment and other surgeries and treatment for back problems and heart disease. When I met Dana she told me that pre-cancer she weighed about 135 pounds and on the day I saw her she weighed 74 pounds and looked as though a strong wind would blow her over.

If instead of recommending hospice, Dana's doctors had pushed for more surgery and chemotherapy I believe Dana would have quickly become proactive and decided against further treatment. Dana could be passive in response to the referral to hospice, because her opinion coincided with that of her doctors (and at the same moment in time). Why was Dana ready to accept hospice care while others faced hospice with fear? Dana's social context offers some hints as to the possible reasons for variation in whether patients accept or resist, fear or embrace hospice care. Dana illustrates some of the personal traits that are relevant to not only the question of "choosing" hospice care, but will resurface later as I examine the myriad choices patients face while receiving hospice

care. Dana's attitudes toward dying, family background, financial circumstances, and her spiritual and religious beliefs are all suggestive of why she welcomed hospice care.

First, Dana had specific attitudes towards dying that led her to welcome the idea of hospice care. Dana made it clear throughout our interview that she believed in an afterlife and was ready, and perhaps even looking forward to dying. When recounting her referral to hospice she mentions that her attitude was, "when it's my time it's my time." Dana's stories about her illness experience clearly show that she was skeptical of medicine's curative power, and believed her cancer diagnosis would inevitably cause her death, even when doctor's told her she was "cured"²⁸. Some might call it a fatalism others might call it realism; Dana acknowledges that she will probably die soon. Dana's illness experience has been long and she has tried many aggressive treatments. Some of the patients who most resisted hospice care were those who were given a diagnosis and then abruptly referred to hospice, like Cliff and Joyce. Spending years dealing with an illness allows some patients to slowly come to terms with the decline happening in their bodies and the probable outcome. Unlike very young patients or patients with rapidly progressing illnesses Dana has had ample time to adjust to her illness and prognosis. Finally Dana's greatest fears are not about death, but about the loss of control and loss of self she might experience while dying. Dana tells me, "I just want to go to sleep and not wake up because I can't picture me needing diapers and having somebody change me. I cannot picture that. I think that alone would kill me." She wants to preserve her

²⁸ For example, Dana explains, "Yeah I knew that cancer will always come back eventually. I had five years... I know darn well deep down that once you got cancer it may be 20 years later but it will come back."

independence and quality of life as much as possible, both goals that hospice care prioritizes.

Second, Dana lives alone and has no substantial worries or concerns for her family when she dies. Other patients expressed considerable anxiety their family members. For example Gene says, “I think my death will be devastating for my wife, because she has always relied on me for all her decisions and so forth. And I think it will be devastating for her... I promised I would take care of her until she died, many, many years ago. And I would like to stay true to that promise.” Family considerations weigh heavily on how patients feel about hospice care and dying and whether they are likely to make a decision that could be interpreted as “choosing dying.” Third, Dana has limited financial resources, making her an ideal candidate for taking advantage of services hospice provides which she would otherwise be unable to pay for out of pocket. Fourth, Dana has a strong spiritual belief in the afterlife, which for her means she views death as less of an ending and more of what she calls a “transition”.

CONCLUSION: SOCIAL MEANING AND SOCIAL CONTEXT

Both the social meaning of hospice care and the social context of patients’ lives heavily influence the decision to transition to hospice care. Patients’ beliefs about hospice coupled with physicians’ actions as gatekeepers determine if and when patients begin hospice care. A small number of patients passively accept physician referrals to hospice, not perceiving hospice as a “choice” but as something that is “chosen” for them. The majority of patients take a more active role, and when physicians refer them to hospice

they respond either by welcoming it or fearing it depending in part on whether physicians present hospice negatively as “giving up” or positively as a form of medical care which will help them live more comfortably and perhaps longer. Patients who equate hospice with “choosing dying” or “giving up” on life are more likely to delay or reject beginning hospice care. I present some evidence that physicians may have the ability to change patient misconceptions about hospice by adjusting how they communicate, a finding also presented by Vig et al (2010). Other patients do not wait for physician referrals, but are proactive in self-referring to hospice. They actively choose hospice for its demedicalizing tendencies, reducing what they see as excessive or ineffective medical treatment. In many cases it is family members who actively seek hospice care for their loved ones. These proactive patients want to stay out of hospitals and nursing homes, and remain in the family home. This subtlety in how patients are referred to hospice and evaluate hospice care is crucial. At the end of a terminal illness delaying weeks or months before starting hospice care is momentous. Misperceptions and stigma mean that some patients may never come around to the idea of hospice or may come around “too late” and either end as the “late referrals” that hospice workers and researchers bemoan.

A patient’s individual social context and the timing of referral to hospice is also critical in decision-making. Dana and her doctor approved of the same course of action at the same time: transfer to hospice care. Patients who proactively choose hospice, like Judith, and opt out are often choosing hospice before their providers recommend it. Patients like Joyce and Gene are referred to hospice before they are ready. When providers recommend hospice too early or abruptly it may lead to resistance and fear, recommending it too late may lead to late referrals or patients who refuse hospice care.

Most health care research conceptualizes these late referrals as a failure of physicians to prognosticate and their bias and reluctance to refer patients to hospice (Brickner et al. 2004; Christakis 1999), this study shows patients themselves often choose to delay hospice care.

Although this chapter concerns transitioning to hospice the idea of social context is relevant to patient autonomy and choice throughout the process of dying and the experience of hospice care. As revealed in this chapter the following criteria are important: (1) knowledge of hospice, (2) attitudes toward dying, (3) family background, (4) financial considerations, (5) religious and spiritual beliefs, and (6) institutional/professional pressures. These factors continue to play a role in patients' experiences once they begin hospice care, as I show in the next chapter. One of the strongest determinants of a patient or family member's decision to begin hospice care is their prior knowledge of hospice and more specifically what meaning hospice care holds for them. The social meaning of hospice care, which equates hospice with choosing to die and giving up, predominate in stories of referrals. Few participants in this study understood hospice as a medical intervention at the time of referral, although the patients that did highly esteemed hospice care.

While this chapter is about the transition to hospice care, it is suggestive of how social meaning and social context might be instrumental in a host of medical decisions, particularly those concerning transitioning from one medical strategy to another. Terminal illness is fraught with weighty decisions and choosing whether to pursue chemotherapy, radiation, participate in clinical trials, or surgeries with uncertain prospects of success may all be construed as choosing to live or choosing to die. Patients

facing these decisions are equally constrained by their personal and spiritual beliefs, financial concerns and family considerations. Even more common ailments and non-fatal chronic illnesses are subject to these same social pressures. In this chapter we see how family members are often a patient's primary caregiver and biggest advocate, working to ensure patients receive what they perceive as the "best" care. This chapter reinforces the idea that nuance matters and physicians often communicate referrals in ways that evoke pessimism and defeat. Educating physicians, patients, and caregivers may be the most effective way to improve the process of transition to hospice care, and more generally transitions from one medical strategy to another.

This chapter is currently being prepared for submission to journals for publication. The dissertation author was the primary investigator and author of this material.

CHAPTER 4. THE SOCIAL CONTEXT OF MEDICAL DECISIONS

Up until now research has predominately focused on the professional and institutional constraints medical institutions place on patient autonomy. This view overlooks the importance of the social context of medical decisions. I note the ambiguity about what represents a “medical decision”; patients make social decisions that influence their medical care and medical decisions that influence their social life. Patient choices are both constrained and enabled by immediate social influences, specifically: (1) family considerations, (2) financial circumstances, (3) attitudes toward dying, and (4) and religious and spiritual beliefs. The social context of these decisions suggests that individual level social context is a very powerful a determinant of medical decision-making.

FROM MEDICAL CONSTRAINTS TO SOCIAL CONTEXT

There is a vast literature within social science and medicine examining how patient autonomy is constrained or enabled within medical settings. Some of this literature focuses on the doctor-patient relationships and how circumstance, language, trust, and professional strategy can facilitate or hinder patient choice. Another strain looks at how institutional characteristics; bureaucracy, regulations, and protocols largely restrict the options open to patients. Much of this literature implies that if we could

change professional-patient relationships and institutional structures patients' preferences would be more likely to be met. A smaller literature questions this assumption by demonstrating how patients' preferences change over time and patients often resist autonomy. However, there has been very little attention paid to how an individual's social context influences medical decision-making. This chapter exposes the manifold ways that social context changes the nature of patient autonomy itself.

In this chapter I highlight some of the choices that hospice patients and their families make, from the big decisions such as whether to consider palliative sedation as death approaches, to the more mundane decisions such as whether to use a pillbox to organize medications. Many of these choices concern hospice care, when hospice workers should come visit or what to talk about during visits. But many choices are life decisions that patients outside of hospice care also face, such as whether to use a walker, use a hospital bed, or stop driving a car. These decisions are often motivated by health concerns, but they are as often decided by social obligations or personal beliefs.

I find that while receiving hospice care patients are subject to four immediate social influences: (1) family considerations, (2) financial circumstances, (3) attitudes toward dying, and (4) religious and spiritual beliefs. A fifth social influence, institutional pressures, is examined in chapters 5 and 6. These social influences operate as independent variables determining what choices patients make. They are often also dependent variables; patients make medical decisions in order to influence a social outcomes, for example to alleviate the caregiving burden a spouse experiences.

Medical Constraints

A rich scholarly literature reveals how the institution of medicine constrains patient choice. A large body of research shows that the doctor-patient relationship can facilitate or hinder patient choice (Ong, de Haes, Hoos, and Lammes 1995). Some scholars show that the “decisions” patients are presented with are highly scripted and presented in such a way that patients are guided to choose whatever the medical professionals recommend (Anspach 1993; Zussman 1992). The very language doctors use when revealing diagnosis or prognosis also tends to lead patients to agree with their recommendations (Lutfey and Maynard 1998; Taylor 1988). Physicians have both cultural authority, credibility, and expertise all of which put them in a position of advantage relative to their patients who are often further disadvantaged by the mental and physical stressors of illness (Starr 1982). Indeed physicians and scientists have a large institutional network buttressing their professional position and the credibility of their knowledge production, while patients are relatively alone (Latour 1987).

Another strain of medical constraint on patient choice involves institutional characteristics such as bureaucracy, regulations, and professional protocols. Certain regulatory and financial structures appear to offer an explanation for why some patients near death are given “heroic” interventions and others are repeatedly and often unnecessarily hospitalized (Kaufman 2005). Bureaucratic, political, and legislative differences between medical care providers in different cities and states means that different hospitals have different norms with respect to their standard of care and whether withdrawing or withholding medical treatment is appropriate (Larriviere and Bonnie 2006; Zussman 1992).

In response to the perception that patient preferences were unknown and unmet at the end of life and as a consequence of several politicized end-of-life legal cases²⁹ various institutional devices designed to further patient autonomy were created: informed consent forms, Do Not Resuscitate (DNR) orders, Living Wills, Advance Directives, Physicians Orders for Life-Sustaining Treatment (POLST), Do Not Hospitalize (DNH) orders, and various legal designations of a proxy or surrogate decision-maker including a power of attorney. These efforts to further patient autonomy appear to be largely unsuccessful. Informed consent forms are often not explained to patients and patients sign them by rote instead of after careful consideration (Akkad et al. 2004; Corrigan 2003; Dixon-Woods, Williams, Jackson, Akkad, Kenyon, and Habiba 2006; Zussman 1997). Serious efforts to improve patient autonomy through clinical intervention in the use of Advance Directives, such as the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, failed to achieve any improvement (SUPPORT Principal Investigators 1995; Teno et al. 1997).

Much of this literature on medical constraints implies that if we could change professional-patient relationships and institutional structures patients' preferences would be more likely to be met. A smaller literature questions this assumption by exposing how patient preferences change over time and patients may resist autonomy. Kressel and Chapman show that patient preferences are heavily influenced by the wording on forms, suggesting that, "End-of-life treatment preferences are not stable, internal wishes that a person easily expresses when presented with a living will" (2007, 306). Other research

²⁹ Most notably the cases of Karen Quinlan, Nancy Cruzan, and Terri Schiavo shaped political and legislative attempts to ensure patient and family member preferences are met. Rothman, David J. 1991. *Strangers at the bedside*: Basic Books, Inc.

shows that preferences change over time such as after hospitalization or as illness progresses (Ditto, Jacobson, Smucker, Danks, Fagerlin, Ditto, Jacobson, Smucker, Danks, and Fagerlin 2006; Ditto et al. 2003). This evidence suggests that there is something about the patient's social context that is a powerful influence of their preferences and the very stability of their preferences.

Drought and Koenig suggest that the "autonomy paradigm" contains three problematic assumptions (2002):

This approach is predicated on three unacknowledged assumptions: The first is that the timing of death can be predicted and that the concept of terminality can be objectively considered, measured, and shared with the patient—all necessary for patients to make realistic decisions about their care. The second assumption is that patients and providers recognize choice as a component of treatment decisions—that there are, in fact, meaningful options available for the decisions they confront that are amenable to individual choice rather than some more fundamental imperative, such as availability of resources or the limits of physiology. Finally, and most problematically, contemporary approaches to care of the dying assume that all individuals can routinely, comfortably, and meaningfully confront and consider not just their own mortality, but also the process of their physical decline and dying, in an engaged and rational manner.

While each of these three issues pose substantial obstacles to decision-making, most of these issues are to some extent overcome in the hospice population, making it an ideal object for further addressing the feasibility of and advantages and disadvantages to patient autonomy. Although not all deaths can be predicted and not all prognoses are shared with patients, in hospice care the majority of patients without severe dementia realize they have been given a prognosis of six months or less to live. Hospice care involves a range of options outside of what are considered standard medical decisions, and hospice care relies on patients to help make treatment decisions. Finally, hospice care

illustrates how the ability and desire to confront mortality shapes many hospice care decisions.

Drought and Koenig emphasize that new research strategies are needed to understand how patient autonomy exists or disappears in practice. They suggest, “Much end-of-life research to date has simply assumed the salience of the choice paradigm, partly because it provides seemingly clear-cut "decision points" to study using quantitative methods, avoiding the messy realities of dying and the need to create new research tools and methods focusing on process” (Drought and Koenig 2002; 2002). They highlight the need for descriptive research that looks at the experiences of patients and their families³⁰. This study aims to provide that lens into the messy and enlightening social context of patients at the end of life.

I argue that using hospice care as a lens into this process we should look at how social determinants outside of the doctor-patient relationship and mainstream health care system influence patient autonomy. In other words how does the patient’s social context influence their care decisions? Does a patient’s family background, socioeconomic status, religious or spiritual orientation, or cultural heritage influence their end of life choices? Sociologists are accustomed to examining how social determinants influence health and

³⁰ Drought and Koenig’s full suggestion reads, “Descriptive research on the experience of patients through the disease and dying trajectory can help us fashion an ethics of end-of-life care that reflects the values and concerns of patients and their families. Is there an identifiable moment or process for recognizing death's inevitability? Is there a point of transition toward disengagement with life? How do patients, families, and clinicians identify that a patient is dying? What are the sources of resistance to this identification and what values does that resistance signify? How are power relationships between clinicians and patients affected? What is the experience of accepting and preparing for death early in the process? What are the costs and the benefits?” Drought, T. S. and B. A. Koenig. 2002. ""Choice" in end-of-life decision making: researching fact or fiction?" *The Gerontologist* 42:114-128.

health care preferences (Wilkinson 1996; Williams and Collins 1995), it should follow that social determinants would also influence health care decisions. Quantitative analysis of attitudes illuminates some trends. We know that African-Americans and other ethnic minorities often resist limiting medical treatment at the end of life and refuse hospice care (Crawley et al. 2000; Gamble 1997; Johnson, Kuchibhatla, Tanis, Tulsky, Johnson, Kuchibhatla, Tanis, and Tulsky 2008; Johnson, Kuchibhatla, and Tulsky 2008). We also know that religion affects attitudes toward many end of life interventions such as hospice itself (Garces-Foley 2006b) and the practices of physician-assisted suicide or terminal palliative care (Burdette, Hill, and Moulton 2005). Yet we know little about *how* these social determinants change health care decisions. Unfortunately much of the related research on the controversial decisions related to end of life medical care depend on quantitative analyses measuring “beliefs” or “preferences” (Benson 1999; Burdette, Hill, and Moulton 2005; Emanuel 2002; Emanuel, Fairclough, Daniels, and Clarridge 1996; Steinhauser et al. 2000; Wasserman, Clair, and Ritchey 2005), which tells us little about what choices people perceive are theirs to make and what actions they eventually take. While some research on Medicare data is able to provide retrospective data on who actually used hospice care and other health care options it too only presents a partial picture. The slice of the pie that is missing allows us to observe health care decisions in the making, through ethnographic observation and interviews with people who are currently facing end of life decisions in hospice care.

A growing literature on the role of family members and caregivers at the end of life suggests the many ways that they contribute to or even steer decision-making (Haley, Allen, Reynolds, Chen, Burton, and Gallagher-Thompson 2002). Haley et al argue that

research must focus on the “family context” of end of life decisions, a task this study undertakes as an important goal (2002). Much of the literature on “caregivers” has grown out of psychological studies of the burden, guilt, and grief which caregivers experience (Aneshensel, Pearlin, and Schuler 1993; Chentsova-Dutton, Shucter, Hutchin, Strause, Burns, Dunn, Miller, and Zisook 2002). In other cases research examines how caregivers influence patients, for example how patients are driven by a desire not to be a “burden” to family members (McPherson, Wilson, and Murray 2007). Some research on family context explores patients and family members in conjunction by doing both individual and family interviews. Carlander et al using this approach in Sweden followed five families in a palliative home care program for five months (2011). One of the drawbacks of this and others studies like it is that it does not offer a comparison between patients living alone and patients living with family members, something my study contributes.

Unlike a literature that mainly shows how the health care system qualities constrain patient choice, this review of the experience of hospice care shows that social context can both hinder and foster medical decisions, sometimes in unpredictable ways. Family members may help patients exert control, but they can also thwart their choices. In some cases patients without close family members appear to be more constrained by their lack of resources, in other cases patients with no family members are freer to pursue their own preference without opposition. Indeed my study illuminates how the very category of “choice” and definition of “medical decision” is malleable.

Expanding the Definition of Medical Decisions

Before analyzing the social context of medical decisions it is necessary to define and draw some parameters around the term “medical decisions.” Medical decisions are not simply the discrete interventions many clinical researchers examine – such as what life support measures patients prefer. Instead medical decisions are embedded in every encounter with hospice care and medical professionals. When and if patients schedule appointments, how they interact with hospice workers, when and why they ask for help, these are all subject to patient choice as well as many constraints on choice.

So how can we define “medical decisions”? A conventional definition might define decisions presented to a patient in a medical setting, such as a hospital, or by a medical professional as “medical”. Whitney and McCullough looking at the perspective of physicians define a medical decision as, “a choice to undertake, or refrain from undertaking, an intervention” (2007, 33). They provide a physician-centric perspective on interventions including examples such as, “Diagnostic tests, psychotherapy, surgery, and the administration of medication or radiation therapy are all interventions” (Whitney and McCullough 2007, 33). The perspective of medicalization suggests that all choices presented by hospice or hospice workers are inherently medical, since they are under the aegis of medical care. Is the work of hospice volunteers a medical intervention? I suggest that most volunteers would say they provide a social intervention. Yet it has been shown that hospice volunteers may confer a medical benefit, as recent evidence suggests patients who meet with volunteers live longer than their counterparts (Herbst-Damm and Kulik 2005).

I suggest a broader conceptualization of medical decisions that includes but is not limited to decisions that have a known medical or health consequence. I suggest that medical decisions also include choices such as: decisions about if, when, and how to communicate with medical or health care workers, decisions about interventions or strategies provided by medical professional or medical institutions, and lifestyle decisions which may affect health or access to health care. This wider definition of “medical” includes many interventions suggested by hospice care workers that would not typically be considered medical. For example, I suggest advice about planning funerals or procuring a shower chair are in a sense medical decisions. I do not suggest that they are solely or even primarily medical decisions, instead I show how medical decisions can simultaneously and even predominately be viewed as social or life decisions.

There exists a tight relationship between medical decisions and life decisions, and this relationship operates in three ways.

1. Decisions may be defined as medical or social or both
2. Social factors influence medical decisions
3. Medical decisions influence social life

In this chapter I aim to expose the complexity and fullness of agency that is available to patients using hospice care. They are not limited to discrete “choices” offered to them by doctors, as they might be as inpatients in a hospitals, they are in a position to shape their experience in more subtle and broad ways. Broadening the definition of medical decisions as I have suggested allows a more complete view of the ways in which patients and their families control or lack control over their medical care.

In my research I was able to witness a range of decisions, many of which that are not observable in hospitals or doctors' offices. Hospice care is unlike other medical care in one critical way, it occurs at patients' homes. Patients and their family members are empowered in their own homes where hospice workers visit as guest-professionals. Unlike doctors' appointments, for which patients call a receptionist and find a time they can be squeezed into the doctor's busy schedule, at hospice the process is reversed. Hospice workers call the patients they are assigned and schedule a time that works for the patient. For some patients who either maintain a passive mentality or who have no commitments hospice workers have a lot of latitude in when they can visit. Other patients carefully select when and why they want hospice workers in the home. One of the big decisions hospice patients face includes which hospice care services they want.

Hospice care is not a one size fits all strategy, it aims to be "patient-centered" and patients and their families decide what care they want. At Pacific Hospice patients are assigned to an interdisciplinary team that includes a nurse, social worker, spiritual counselor, and home health aide. They are also eligible for a range of other services including volunteer services, grief and bereavement counseling, and more specialized options. While there are Medicare regulations concerning some aspects of hospice care, e.g. each patient must be seen by a registered nurse (RN) at least once every 14 days, many aspects of care are voluntary or flexible. Patients decide whether they want services including spiritual counselors, home health aides, and volunteers. They also decide (within regulatory parameters) how often they will see the nurse and social worker, and they often set the tone and agenda for these visits. Depending on personal preference and medical needs one patient may see his nurse 3 times a week, another may see her nurse

just twice a month. Nursing visits may be strictly about medical treatments, or patients may have a deeper relationship with the hospice workers, see them as friends as well as professionals and talk about family, vacations, or their very personal concerns and fears. Patients decide whether they want to see a spiritual counselor or a volunteer, or whether they want help bathing from a home health aide. Throughout the course of hospice care patients are also exposed to a host of decisions that have to do with their day-to-day care and managing their illness. They participate in deciding what medications to use, when to adjust medications, what medical devices to use, whether to use a catheter, wheelchair, hospital bed, or adult diapers. I contend that types of decisions are both medical and social decision and have ramifications in both arenas.

I examine four immediate social influences on medical decision-making: (1) family considerations, (2) financial circumstances, (3) attitudes toward dying, and (4) and religious and spiritual beliefs. I turn to family considerations first as these topics were always at the forefront of discussions with hospice patients.

FAMILY CONSIDERATIONS

Since dying is not only an individual-patient experience but also a social-familial experience, one of the largest determinants of patient choices is family. Family considerations shape what choices patients make about medical care, and as a corollary medical decisions have a profound impact on family's daily lives. At the most basic level patients and their families determine what type of presence hospice care will have in their lives. As one social worker, Kathy, explains to me hospice workers "customize their fit."

When I ask her how often she sees patients she replies that Medicare regulations state she needs to see her patients once every four weeks, but that she has to be very flexible because patients needs and preferences change.

So if you're faced with a patient it could be as broad or as narrow as the patient wants. We had a birthday party yesterday, we are, our team, is really his whole life, other than his wife. We are really the only people that he sees. So he was in tears at the birthday party... So that is not a typical thing that we normally do, but because of our interaction with him, that's a situation where we'll spread out our visits. I'll go one day, the nurse will go the next day, because that constant socialization, he's not in a lot of pain, but he just appreciates the social part. We have other patients who have a large extended family, they want to always pretend that they are not on hospice, so really they just want the nurse to come out when they need her or when they need to refill medication and they want us to sort of fade into the background. So we can customize our fit.

The patient Kathy mentions above who had a surprise birthday party thrown by hospice workers did not “choose” to have a party in the conventional sense. His control over hospice care is subtle. He let hospice workers know how much he appreciated having frequent visits from hospice staff and they responded to his cues. Some patients, particularly those who are living alone or without family prefer lots of contact from hospice workers. Other patients with large families or extensive support networks prefer minimal hospice involvement. Sometimes the effect of family status seems to be contradictory. For example patients with family members living with them or nearby often benefited by having advocates and loving caregivers. Patients living alone seem comparatively bereft of assistance. However, patients living alone sometimes appeared freer in their choice of hospice services they desired, they did not have concerns about how hospice workers in their home might affect other members of the household. Patients like Gene, living with his wife, daughter and two grandchildren, were concerned about

how hospice workers in the family home might be problematic for other family members. Just as in the last chapter we saw how family often influenced pathways to hospice, here I examine how family background influences what types of hospice care patients desire and receive.

In many cases family circumstances shape patient decisions. For example Dottie, the 94 year old with a diagnosis of “Debility Unspecified” provides a good example of this complexity. Her illness experience and the trajectory of her disease severely constrained the choices she can make. She has lost the ability to stand and walk unassisted and has been bedbound for an entire year when I first met her. She can no longer make taken for granted choices such as when to get out of bed, what to wear, what to eat for lunch, or when to shower. To the extent that she controls these decisions it is because her son, Doug, or the hospice workers offer her certain choices. Also severely constraining her choices are her family/social background and financial considerations. She lives alone (although her son Doug lives in a detached home on the same property). Her son is her only remaining family member within a thousand miles. She has no remaining friends due to her advanced age and an unusual falling out with her church friends over her questioning church doctrine. Because she and her son share modest financial resources they are unable to pay for a hired caregiver. Consequently Dottie faces pervasive loneliness and sadness and her son faces burnout as her only caregiver.

These factors specific to Dottie’s illness, her family and social background, and her lack of financial resources lead her to choose to take advantage of a wide range of hospice care services. She is particularly happy to have two volunteers assigned to her. These volunteers serve a dual purpose, they provide social interaction and companionship

to Dottie and they allow her son Doug time to leave the house knowing his mother has someone there if a problem arises. As Dottie explains: “To lay here all day long with no company, that would be terrible. Visitors mean a lot when you are down for a whole year flat on your back. Without them I don't think I would make it that long.” It may be true that social contact, in particular visits from volunteers may in fact help her live longer (Herbst-Damm and Kulik 2005). In her case, as hospice staff explained to me, hospice workers have strategized their schedules so that they are out her house every day each week, except for Saturday and Sunday (but Dottie says they even sometimes come then). The social and emotional attention the hospice workers provide is literally a lifeline to patients like Dottie. In this sense choosing hospice services serves a social purpose as well as a medical purpose.

Social or medical decisions?

The acknowledgement that a decision is both social and medical does not necessarily confer greater patient control, in many cases it makes patients' decisions more complex and difficult to make. Although Dottie proactively chose hospice for herself by self-referring, she resists making some choices due to their social and financial complexity. In an interchange I observed between Dottie and her hospice nurse Ellen, Dottie tells Ellen that her catheter causes her discomfort and she is experiencing a horrible sensation of needing to but not being able to urinate. Dottie has described this sensation to me on other occasions and it is not the first time she has raised the issue with her nurse. Ellen and Dottie discuss the pros and cons of switching to using adult diapers

as an alternative to the catheter, including the fact that Medicare will only pay for the less desirable type (tape-on instead of pull-ups) and the increased burden this change would place on Doug who would be responsible for changing her diapers. Finally Ellen asks if Dottie would like to make the switch and Dottie replies she wants to do “whatever the doc thinks is best.” Ellen tries to explain to her that this is a personal decision that needs to be based on her comfort, but Dottie resists making a decision and by default continues to use the catheter.

This reluctance to decide may look like deference to medical authority, but I argue that it is just as much a result of the social complexity of this decision. Like other elderly patients Dottie may have an ideology of medicine in which doctors make most decisions and she goes along for the ride³¹. However, family considerations suggest she may avoid making this decision for social reasons. Her decision affects family finances since the nicer diapers are more expensive. Dottie’s decision also affects her son’s caregiving burden. If she switches to diapers, he will spend more time doing more intimate physical work taking the diapers on and off. During my interviews and observation Doug and Dottie both made it clear that they are uncomfortable with Doug caring for and cleaning Dottie’s groin area³². Dottie’s family gender structure (specifically that she has a son instead of daughter) appears to makes decisions about requiring bodily care especially difficult for her. Because she is widowed she relies on her only child, a son, for everything from changing her clothes to helping her use the

³¹ Colleen’s mother, who was also in her 90s, similarly adopted a passive role with doctors as Colleen notes when describing how her mother always told her doctor “I’m fine,” whenever he asked.

³² Indeed on this same visit, Ellen asks Doug to pay more attention to cleaning Dottie’s groin, noting a growing sore on her skin.

toilet, a dynamic she found very painful and embarrassing. During another a visit from her nurse, after she watched her son empty the urine bag from her catheter into a bucket and then carry it into the bathroom to pour it down the toilet, Dottie turned to us and said, "You never expect a son to have to do that for his mother. Carry my piss pot." Dottie resists any changes that might impose a further burden on her son. Later on Doug tells me that he has back pain that is exacerbated by the heavy duty lifting he does dressing his mother, changing her, and helping her on and off the toilet. This example illustrates how what appears to be a medical decision, whether to use a catheter, is also a social decision with serious financial and family caregiving consequences. For some patients it may be easier to ask a medical professional to make a decision than to assume the responsibility of making a decision with such profound consequences for the family.

The social consequences of decisions often weigh heavily on patients who feel guilty about the burden they are placing on family members (McPherson, Wilson, and Murray 2007). In the next example, I show why Steve resists a medical recommendation to use TED Hose stockings to reduce the swelling (edema) and circulatory problems in his legs. As a home visit between Steve and his nurse Eva progresses it is revealed that Steve cannot effectively put on the stockings by himself and he does not want to ask his wife for help.

As we sit down Steve tells Eva says he has been having pain in his right ankle since this morning. Steve says, "I hope it's nothing" implying that it could be a sign of something worse. Steve mentions he had his masseur (a hospice volunteer) visit yesterday and he worked on his legs, which have a lot of swelling, and it felt great. Eva asks if he is wearing the support TED hose. Steve says he is not, it is too hard for him to put them on in the morning. Eva says they will be easier to put on if he does it first thing in the morning (she winks at him).

Steve complains about how uncomfortable his swollen legs are. He says it feels awful "like he's being invaded." He mentions that the skin on his leg is getting glossy. Eva says that it gets shiny like that from the swelling and the skin stretching (edema). Steve asks why the swelling, Eva says it is from the tumor in his abdomen, which puts pressure on lymph nodes and creates fluid build-up. Eva and Steve discuss different options for reducing the swelling. Eva kneels on the floor in front of Steve and asks him to pull up his pant legs so she can examine them. Steve right hand cramps as he tries to pull up pant leg, and he withdraws his hand quickly, his fingers arched back in pain. Eva takes over and rolls up his pants...

Steve says he is having a lot of trouble putting TED hose support stockings on in morning (black tight socks that go up to right below knee). Steve explains that because of his protruding belly he can not bend down far enough to put the socks over his feet. He shows Eva how he tries to cross his legs to put on hose, but that hurts his feet. Eva asks if his wife could help put hose on while he is still in bed. She explains it is easier to get the stockings on before he gets up because as day progresses the swelling will get worse and worse. Steve resists this suggestion. Eva puts the TED hose back on, even with her being an expert it takes some time, maybe five minutes and does cause him some discomfort. Steve says, as she is gently arranging the hose "you're such a great nurse," Eva says "thank you."

Steve does not want to impose another burden on his wife and our further conversation revealed possible reasons. He is often exhausted in the morning and likes to sleep late, but his wife goes to work early and is busy in the mornings. Steve's nurse Eva confides in me later that she thinks Steve's wife is having a difficult time facing her husband's deterioration and this too might factor in to both Steve's reluctance to ask and her reluctance to provide further assistance to him.

Family members also exert tremendous influence over patient decisions about which hospice services to use, as in the example of hospice volunteers. Hospice patient care volunteers are generally assigned to either provide patients with companionship or caregiver relief. Caregiver relief is intended to provide a volunteer to be present with a

patient allowing the family member/caregiver to have some time alone to relax, do errands, or simply not worry about the patient for a while. One long time hospice volunteer, Harold, told me that he once had a patient who declined to see him again after only one visit. He was assigned to this patient for caregiver relief, and the first time Harold went to visit him the patient's wife referred to Harold as "the babysitter" in an unkind and chiding manner. Harold is convinced that this patient cancelled volunteer services after this visit due to his wife's demeaning attitude.

Sometimes it is not family per se, but hired caregivers or friends who influence a patient's decision. I observed a visit between Cliff and his nurse Ellen in which changes to medications and medical equipment came up repeatedly. Cliff has ALS and is gradually losing his mobility. He is developing bedsores on his tailbone, one of the common side effects of sitting and sleeping in one place (his favorite recliner) too long. Ellen tries to convince Cliff to sleep in the hospital bed provided for him, but Cliff firmly resists and Ellen turns her attention to how to treat his bedsores. Cliff does not want to show Ellen the sores (perhaps because I am in the room as well and they are on his buttocks). Ellen queries him about how he is treating them, finds out that he is applying the wrong ointment, and goes to her car to get him the correct ointment and a special butterfly shaped bandage called a "hydrocolloidal" that will operate like a protective layer of skin.

Ellen even brings a stuffed teddy bear back from her car to demonstrate to Cliff exactly where the bandage should go. Cliff seems apprehensive but willing to try it. Then Ellen tells Cliff he can not put on the bandage himself since he cannot see the area. Ellen calls Lucia, Cliff's hired caregiver into the room to ask her if she is willing to put on the

bandage. Lucia says she is willing but says she does not think Cliff will let her do it. Cliff now seriously resists the bandage idea. He says, “How will she put it on my bottom?” Ellen replies in a serious voice, “You are going to let her.” Cliff protests some more saying Lucia will “faint” if she sees his bottom. Lucia seems skeptical repeatedly asking Cliff through the conversation, “Are you going to let me?” After all Cliff is her employer and he ultimately determines what she does. The conversation turns to other topics and forty-five minutes later we leave Cliff’s house. On our way out Ellen stops to speak to Lucia in private reminding her to do the bandage and call her if Cliff refuses. As it turns out I see Cliff a couple of weeks later and I ask Lucia what happened and she said he never let her put the bandage on him. Here social concerns prevent the use of a medical intervention. Cliff decides his modesty overrides his concerns about the bedsore becoming worse or infected and refuses to let his caregiver apply it. If Cliff’s wife were still living he would no doubt simply have her apply the bandage, but he like other widowers and people no family caregivers face these difficult choices. Patients with no family (or no family nearby) present a special example of how family or lack of it influences medical decisions.

In the examples above we saw how patients make choices for social reasons or to avoid social consequences. In other situations family members make decisions for patients. As demonstrated by Dottie, many choices are restricted for patients once they lose mobility. As Dottie’s condition deteriorated her independence was limited even further when her son made the decision to move her hospital bed out of her bedroom and into the living room. I observed a meeting between Dottie and her social worker, Dennis, in which he asked Dottie how she felt about the move to the living room. Dottie said it

was her son's decision and she did not like it. Dottie's old bedroom was small and cluttered; putting her bed in the center of the living room allows her son to more easily help her. There is space for a toilet chair right next to bed, space for visitors to sit, a TV for her to watch, and more space for her son and the hospice home health aide to help her with toileting, bathing, and dressing. Yet, although this change benefits everyone else it removes Dottie from the comfortable bedroom she enjoyed as her personal space.

In some cases family members determine not only what hospice services patients receive, but also even whether hospice patients are told they are receiving hospice care.

In an interview with a social worker, Megan, she described to me how this happens.

I have so many people [say], "don't use the word hospice. Hide your name badge." Family members will try to protect family members [patients]. They'll say—a lot of times they'll say, "you're not a social worker." I'm the "nurse's helper". I just go along. I just go along. I mean, what eases it—I mean, what's the difference? And honestly—and then we just go along with it and we use words like, "we're just here to make you comfortable." You know, "we want you to try to find as much quality as you can." Stuff like that. We don't have to use it [the word hospice].

Megan says families who interpret hospice as "giving up" on life do not want patients to realize they are getting help from hospice care. When she goes to see these patients she removes her Pacific Hospice name badge before she walks in the door. While it is difficult to imagine hiding this knowledge from some patients, patients who have dementia, who have already lost some ability to communicate, or who are drifting in and out of consciousness might easily not realize the difference between hospice nurses and other visiting nurses. In these situations family members make critical decisions for patients.

Family members can also decide what specific tasks hospice workers will do. In her interview with me, a hospice home health aide, Anna, describes a patient of hers who died the night before our interview, “So I was there. We changed her -- we went ahead -- it was bothering the daughter that, you know, she was wet, and so we managed to change her in a recliner chair. A first for me.” Anna tells me that the patient was so close to death that it was impossible to know if she was bothered by being wet. However, her daughter was disturbed that she had urine on her so Anna and other hospice workers changed her clothes.

Anna describes another situation in which family members made decisions that may not have been advantageous or may even may have been harmful for patients, but with patients who are unable to communicate it is difficult to know. In this case a patient’s daughter wanted her to have regular showers, Anna recounts that this patient had severe Alzheimer’s and would scream throughout the entire shower, and would sometimes faint in the shower. In Anna’s opinion, “This poor patient just needed to be left alone, maybe a bed bath.” However, the patient’s daughter had just remodeled her shower to allow her mother to use it and she insisted. Anna explains, “It was just all, you know, for the daughter. What does the daughter need from us? What does she want? She wants a shower. And then for a while it was like well that's when she has a BM [bowel movement] in the shower. It was true for quite a while so we're like okay. That's why she could justify for three days because that's when she had a BM.” The hospice team was able to justify continuing the showers despite signs that the patient resisted them because of the daughter’s preferences and the fact that the patient only had bowel movements in

the shower³³. This case also illustrates that with patients with severe dementia, and indeed often when patients are unconscious at the end of their illness family members by default take on all decisions and “speak” for the patient.

Family as recipients of hospice care

While family members often make important decisions for patients they are also the beneficiaries of many hospice services, and they are recipients of hospice care in their own right. Many family members stressed to me the incredible assistance and comfort hospice provided to family members. Colleen, the volunteer whose mother received hospice care describes how she used hospice services and how they helped her.

But whenever I called they were there, either on the phone telling me what I needed or actually before the stroke mom had some COPD crisis which they -- it has a name, a retraction. She was -- usually it's precipitated by a cold, but often it happens for no reason at all and all of a sudden patient is breathing in a very labored manner, and when you are old you haven't got that kind of energy and muscle. It's very bad. Hospice showed up at 4:00 a.m. bam, and helped her. And during her last two weeks taught me what I needed to do to help her in a lot of situations. They were always there for me and for her, and that is an unspeakable comfort when what you need is not, you know, mental comfort. You need somebody to tell you how to make someone feel better.

For many caregivers hospice not only provides instrumental support by teaching them how to care for patients, it provides solace and security. Other caregivers spoke of support they received from hospice ranging from grief support groups, to individual

³³ Tracking and ensuring that patients have bowel movements is an important part of the hospice workers' responsibilities. Many of the pain medications patients take cause constipation, which can lead to painful and life threatening complications if patients go too long without a bowel movement and develop an obstruction.

bereavement counseling, and supportive relationships with hospice workers. Caregivers who involve themselves with hospice care consequently receive more help. Those who are present for meetings with hospice workers and who call the hospice team members are choosing to be involved and receive assistance. Other family members recede into the background such as Steve's wife who was always at work and rarely met hospice workers, and Gene's wife and daughter who lived with him but they made themselves scarce when hospice workers came to the house.

Other caregivers like Deborah, Jerry's wife, sought out extra help from hospice workers. For example, Deborah told me she routinely asked Maeve (her husband's hospice nurse) to go over with her how to administer the medications, such as morphine, kept in the emergency medication kit in the refrigerator. The hospice team came to know Deborah well as she was always present during her husband's hospice visits. They referred Deborah to grief counseling which she found comforting. On a visit between Jerry and his nurse Maeve, I observed that Maeve also checked Deborah's blood pressure after she checked Jerry's vital signs. Deborah had told me earlier that she had a history of heart problems and was concerned about her blood pressure rising unexpectedly, a health concern she regularly discussed with Maeve.

Just as family members can help or hinder patient's hospice care experiences, so too can patients add or detract from family members experience of hospice care. In some cases patients encouraged family members to communicate with hospice workers and receive assistance such as volunteer services or grief counseling. In other cases patients, sometimes inadvertently, limited the assistance hospice provided to their family members. Home health aides and volunteers providing respite (caregiver relief) services

are a form of assistance to caregivers who may be overwhelmed with the physical and mental tasks of caregiving. Patients who refused these elements of hospice care were effectively increasing the caregiving burden on family members. Anna, the hospice home health aide I interviewed said it was common for family members to continue bathing hospice patients even when it was physically too difficult for them, because the patients did not want a “stranger” giving them a bath. As Carlandar et al note, caregiving can be emotionally and physically grueling for family members and they often end up putting their own needs aside and putting the patients needs first (2011).

Sometimes the influence of patients on their family members use of hospice services is quite subtle. For example, unbeknownst to him Henri’s own refusal to see a hospice spiritual counselor meant his wife did not have the opportunity to see a spiritual counselor³⁴, something she suggested to me that she would appreciate. In a joint interview with her husband I asked Henri and Sandra whether they had ever met with the Pacific Hospice spiritual counselor. Henri told me how he emphatically refused that branch of hospice care. After he finished speaking his wife Sandra launched into a description of her own spiritual history and then told me:

So, as far as the spiritual support in the hospice situation. I think the key does have to be to address the patient's needs first, but the reason I'm explaining my situation is that his need is to have no religion or spirituality addressed with him. And my need is the opposite. So a consideration for the differing needs within the family. I mean you might

³⁴ This example suggests two trends. Patients can limit their family members use of hospice services through their own refusal of certain services. Secondly, hospice workers like spiritual counselors may have to actively seek out family member opinions about whether they would like to meet, rather than relying on patients to speak for family members. Spiritual counselors at Pacific Hospice told me their services were explicitly intended to be for both patients and family members so this effort would be within the parameters of their job.

assume that siblings of the patient or children of the patient, I think you would generally expect that spouses would be pretty much on the same path. But that is not necessarily so.

Her husband immediately chimed in saying that Sandra had been going to a wonderful church for more than a decade and had a lot of support from the church. As Henri put it, “I’m not sure that hospice is going to provide any additional support to what you have from your association with Unity [church] for all these years. I mean how many years have you been going?” What followed was an extended back and forth between Henri and Sandra about their spiritual differences, with Sandra tactfully yet consistently telling me that she would have appreciated some spiritual support from Pacific Hospice. As Sandra told both me and her husband, “And I do have the support from people I know at church, but there is, I would think, some, even though I feel that I have had a lot of experience with death. I feel that someone who is a chaplain for hospice would have something to offer me or support me that is different.” Sometimes family members and patients are on the same page, sometimes they are not, and depending on the topic they can both hinder or help each other with respect to the use of hospice services. As mentioned earlier, the patients who lived alone, while disadvantaged in many respects were notably less ambivalent about which hospice services to use since they only needed to consult their own preferences to make a decision.

In the examples above I show how decisions about hospice care are contingent upon relationships between patients and their family members. The very presence of family members in a patient’s home changes the dynamic of inviting hospice workers into the home. I show how decisions about medications, medical devices, and hospice

services can alter the caregiving burden faced by a patient's family members. It was also striking how often social familial considerations involved a careful weighing of the financial pros and cons of certain medical decisions.

FINANCIAL CIRCUMSTANCES

Financial concerns are of paramount importance when patients are facing a terminal illness; many patients and family members confided in me that financial considerations were a significant factor in the decision to begin hospice care in the first place. Particularly important to many patients is the provision by hospice of home health aides to help with bathing, a service they would otherwise need to pay for out of pocket. Rose, a 90 year old with COPD who lives on a limited income with her disabled son, expressed excessive gratitude about the care she received from hospice, particularly having a hospice home health aide come give her showers three times a week³⁵. Rose told me she was unable to pay for home health care prior to beginning hospice and she is afraid to bathe alone, "I wouldn't go in that tub without their help." Due to her COPD she has great difficulty breathing, like many other patients I visited she was on 24-hour supplemental oxygen and walking twenty feet was exhausting to her, the physical effort of bathing was simply too much for her to handle. She had such a fear that she might not be able to get help showering if something happened to her hospice services that she told me she had stocked up on baby wipes, which a friend suggested could be used instead of

³⁵ Rose repeatedly told me she thought patients were only supposed to have an home health aide give them showers twice a week and she was worried if someone realized her aide was coming three times a week she would lose that extra visit.

a shower if need be. Rose's anxiety about finances leads her to regard hospice as a life necessity, not a luxury, and the idea of losing hospice care services provokes great distress.

Financial considerations also affect patients' ability to procure medical equipment they may need as their health declines. The aforementioned example of Dottie trying to make a decision about using a catheter or adult diapers, was simultaneously both a decision about what type of caregiving burden to impose on family members and how much the family could afford to spend on diapers. While Medicare pays for most necessary equipment it does not pay for certain desirable items, like pull-up diapers, or hand held shower heads (which make showering much easier for seated patients). In other cases patients do not realize that Medicare will pay for an item and buy it on their own. Judith explained that instead of spending a "small fortune" on a bath chair from a medical supply company, she bought a plastic lawn chair for \$4.95 that she used in the bathtub when she was a caregiver for her brother with Alzheimer's and which she now uses for herself.

Even when financial considerations do not directly influence discrete choices, they impact patient's level of stress and anxiety. For example, Dottie expressed lingering fears about the cost of hospice services despite being repeatedly told that Medicare paid for hospice and she would not be billed. While observing a visit between Dottie and one of her volunteers, Colleen, Dottie brings up her concern that, "one day there will be a rude awakening and I will wake up and have a huge bill." Colleen reassures Dottie she will not be billed for hospice care, but Dottie's past experiences with other medical care and her limited financial resources leave her some anxiety on this topic.

Patients like Dottie who are bedbound and have limited family and financial resources face the most anxiety and constrained choices with respect to hospice care use. Patients with less limiting illnesses, greater financial resources, and bigger family or social networks experience more flexibility in their choices about which hospice services to use. Florence is a 98 year old with heart disease, who lives in a sprawling home with her daughter and son-in-law, and is attended by two hired caregivers who provide 24 hour 7 day a week care for her. She is an affectionate and stylish woman whose limited mobility forces her to use a wheelchair, but she still regularly leaves her house for social trips, hair appointments and other events. She is offered the same range of services as Dottie, but she wants the minimum of hospice services and limits hospice care to brief nurse visits every two weeks and monthly social worker visits. Based on their descriptions of their hospice care to me, Florence averages 3 hospice workers visits per month, meanwhile Dottie sees hospice workers approximately 23 times per month³⁶ and often even more.

Financial considerations influence how patients live day to day: what they can afford in terms of housing, help, and comforts. Decisions about transitioning to a new living environment were commonly made by patients (or family members) when health was declining fast or financial resources were dwindling. Most of the patients I met were in comfortable homes, although some were fearful of losing their homes due to being unable to pay rent, mortgage, or other bills. Gunnar, an 80 year old with Cirrhosis, was

³⁶ Dottie reports that she has a home health aide who comes 3 times a week to provide baths, a nurse who sees her every week (and sometimes more often), a social worker she sees 2 times a month, and 2 separate volunteers who each see her once a week for four hour long visits. The hospice workers strategically plan visits so that she is seen every day Monday-Friday and she is sometimes seen on weekends when a need arises.

forced to sell his home to pay off a loan and he moved into a board and care facility where I met and interviewed him.

The expense of hired caregivers was often related to decisions to move to a facility. Charlie explained to me how expensive a hired caregiver is, and his concern that he may have to sell his house to continue paying for medical care. He is now looking into board and care homes for his wife who has Alzheimer's and needs 24 hour care. Charlie says with resignation that he believes moving his wife to a board and care home will speed her death, but he is constrained by his financial resources. I observed a meeting between Charlie and his social worker, Megan, in which he reveals that his retirement account has dwindled from \$123,000 to \$13,000 during one year of paying for round the clock home health care combined with the downturn in the stock market. Charlie reflects on these decisions about how to pay for care for himself and his wife, "This has caused more problems in the family than anything else in our lives." He describes how his children have alternately disagreed with him and with each other about how to use the family's financial resources. Not only do financial and family considerations influence when and if patients move to a facility (or move in with adult children), but these decisions often spur conflict within families at an already difficult time.

Financial concerns are a common reason patients need to move into a facility. In one case outright financial abuse of patients by family members was the cause. June, an 89 year old with a diagnosis of Debility Unspecified living in a board and care home, reported that one of her daughters stole money from her bank accounts, leaving her in a position where she said she needed to sell her home to pay off expenses. She then had to move into the board and care home; she has not spoken to this daughter since that event.

Financial considerations are tightly intertwined with family considerations. Financial incentives and disincentives can shape which patients enroll in hospice care, which services they use (especially true for home health aide assistance), and which medications and medical devices they are able to procure and use. The financial element of end of life care is complex and often requires an understanding of a entire family's financial resources. In cases like that of Florence she had very little money of her own, but her wealthy children were paying for a plethora of medical care and devices. Finally, it is a combination of the severity of the patients' illness and needs, the strength and size of their social and familial network, and the amount and accessibility of their financial assets that predict how financial considerations shape their care decisions.

ATTITUDES TOWARDS DYING

Attitudes toward dying are strong influences on choices about hospice care. Although attitudes towards dying are often transitory and shifting, some trends were still observable. Patients who profess that they are "ready" to die are more likely to both want and seek a range of hospice services. Patients who are particularly fearful of dying or reluctant to perceive their condition as deteriorating often refuse services, in some instances furthering their own pain and suffering by declining care that could alleviate their burden.

Patients that told me they were ready to die tended to take advantage of the whole gamut of hospice care services. Judith, the 92 year old living on her own with a rare heart disease, explains her stance:

Number one, I'm not afraid of death. So I'm not agitated in any way about the fact that I'm going to die. Number two, I am willing to die. When it comes it comes, it's an adventure, and I have no fears. I was reading up on... what was Spinoza called? [Judith can not remember name of person she wants to refer to] Anyway there is another man about the same era, and his name is - I've got it written down but I don't know. Anyway I was reading about him and I came to a place where he said: for he who loves his fellow man, will never know pain or fear of death. And suddenly I know why I'm not afraid.

Judith embraces the full range of hospice care services, including have a home health aide come bathe her, a spiritual counselor who she considers, “one of my best friends in the whole world”, and a volunteer who meets with her on the weekend. Judith’s acknowledgement of her impending death also led her to self-refer to hospice. Judith’s willingness to perceive herself as dying and consequently needing and wanting a variety of assistance is one factor³⁷ in her use of a wide range of hospice care services.

A readiness to accept that one is dying leads some patients to embrace hospice care. Dottie, the 94 year old with a diagnosis of Debility Unspecified who has been bedbound for more than a year when I met her, tells her nurse and me during a discussion of her many discomforts, “I'm ready to go now.” Dottie chooses to use the maximum possible hospice care services, and although financial and caregiver motivations are also apparent in her case, her acknowledgement that death is near is a determining factor. Dottie was one of the patients who proactively self-referred to hospice before any doctors recommended it.

³⁷ Judith’s status as a single person living alone and far away from family and her limited financial means may also contribute to her readiness to receive all types of hospice care services, as may her spiritual beliefs, a point elaborated upon in the next section.

Another patient who professes to be ready to die is Dana, a 79 year old with lung cancer who lives alone. Dana is more selective about which hospice care services she uses, something she attributes to her strong independence and pickiness about which people she has in her home. However, Dana tells me her decision to start hospice care was a reflection of the fact that she acknowledged her death was near. Here she describes feeling out of place both at home and outside her home.

I say I don't belong out there because we can't do anything. We can't go shopping or go to the movies and stuff anymore because I get too tired, so it's like I can go in the car but I don't belong out there, I don't belong in here not doing anything. I'm waiting to go up there [heaven], so my life as far as I'm concerned is over and all that I can do is make the best of every day that I can here and try and get along with people and try and be nice and not to be rude. Because I can't do anything anymore and I can't sit here, my clothes cut into my skinny body. I weigh 74 pounds for crying out loud. I can't do anything, so I can't enjoy life like everybody else can. You know food, I have don't have an appetite and I don't enjoy it like I used to.

Patients who do not think of themselves as dying make different choices. Gunnar, an 80 year old with Cirrhosis, discusses his pain medication with his nurse, Becky. He is complaining of back pain and Becky suggests that she could ask his doctor about increasing his dosage. Gunnar resists the idea saying, "it might be habit forming." Like many hospice patients Gunnar worries about becoming addicted to painkillers and Opioids (like morphine). He does not see his life as ending soon and consequently is worried about the addictive properties of certain drugs, a fear hospice workers dismiss³⁸.

³⁸ Most hospice workers I talked to dismissed patient concerns about addiction by explaining that patients were not expected to live long enough for addiction to be a concern.

Gunnar is making decisions based on the future, in his mind death is not an imminent part of that future, but he is worried about other forms of decline such as addiction.

Florence is another patient who fears dying, but does not view herself as dying, and consequently rejects many hospice care services. Florence is a 98 year old with heart disease, who lives in a luxurious home with her daughter and son-in-law, and is attended by two hired caregivers. She wants the minimum of hospice services and limits hospice care to brief nurse visits every two weeks and monthly social worker visits. While she speaks very positively about the care hospice does provide to her, the stigma of hospice and the idea that hospice means she is going to die soon, leave her with lingering reluctance. Florence feared starting hospice care because she had two close friends die quickly after they began hospice care began. Consequently her prior knowledge of hospice leads her to think of it as a death sentence. She describes her reaction when her doctors first suggested hospice, “And it was sad for me and every time you mention the word [hospice] I thought Holy Moses, I don't want it. I don't want to hear it.” She wants to limit hospice involvement in her life and maintains a fear of the actual inpatient hospice facility, “I mean it apparently is a good place for a few people that are ready to pass on, but I haven't gotten there yet.” Florence’s own beliefs and uneasiness about dying are one factor limiting the hospice care services she will consider.

In many cases the patient’s outlook changed gradually over the course of a long illness. Hospice workers told me that often, as their health declines, patients and family members become more ready to die and accept further hospice services. Ellen, a nurse, pinpoints when patients lose the ability to communicate and lose the ability to control their body as turning points when their mindsets may also change. She distinguishes this

moment as when patients begin to “give in” to dying, “That’s also a big thing, and that’s a time – at least I think a lot of people start per se giving up, or giving in to...” When I ask her if giving up is different than giving in, she replies, “You know like giving up sounds like resigned, like and dragging your feet, or depressed. And I don’t mean that. It’s they give in to it, they... accept it, you know.” Ellen is highlighting a natural shift in patients’ willingness to face the idea that they are dying, and to consequently seek further care from hospice, or from family caregivers.

Since most patients in this study experienced a relatively gradual decline in their mental and physical abilities they were able to anticipate and react to these changes, often by requesting more help with activities of daily living such as bathing, dressing, cooking, eating, driving, attending doctor appointments, housekeeping, taking care of pets, etc. However, some patients remained resistant to the idea that they were dying, either foregoing hospice services that would have helped them or their family members or accepting it with reluctance. The trend noticed in this study was that patients who appeared more ready to accept that they were dying were more prolific and satisfied users of hospice care services. However, attitudes toward dying were often dependent on religious or spiritual beliefs about dying, which also had a powerful effect on patients and families.

RELIGIOUS AND SPIRITUAL BELIEFS

An important subset of patient and family members attitudes toward dying is religious and spiritual³⁹ beliefs about dying. Religious and spiritual beliefs about dying often influence patients and family members in contradictory ways, in some patients they provided solace and comfort, in others they caused anxiety and stress, in some patients they seemed to produce both effects in turn. Spiritual beliefs not only impact a patient's general attitude toward dying, thereby influencing their willingness to accept hospice care in the first place, but they also play a role in making decisions about ongoing care, most notably whether a patient is willing to see a hospice spiritual counselor.

Spiritual counselor services are always optional for hospice patients and their families, and patients often choose to decline these services. Patients sometimes declined spiritual counselor services because they were not religious or had no spiritual beliefs and they believed (erroneously hospice workers would say) that this service was only for those who believed in God. Other patients were fervently religious or spiritual and felt that they did not need a spiritual counselor prying into their beliefs and thoughts. Dana, the 79 year old with lung cancer who lives alone, tells me she is a very spiritual person who strongly believes in the afterlife. While she had a spiritual counselor in the past that she really enjoyed talking to, he was promoted to a supervisor and Dana dislikes his

³⁹ For the purposes of this discussion I will use the term "spirituality" to refer to both religious ideas, as well as a more personal set of guiding principles that govern one's beliefs and hopes. One of the hospice spiritual counselors gave me an evocative description of the difference between religion and spirituality. Marc told me, "I saw a diagram once that really spoke well to this. And it was a big rectangle, and that rectangle was labeled spirituality, and in the lower right-hand corner was a little box, a little square, labeled religious." Likewise for the purposes of this analysis I assume spirituality is a broader concept and religion a subset of it.

replacement. Interestingly she has not told any of the hospice workers she wants to completely discontinue spiritual counseling, she simply refuses to set a time to meet with the new spiritual counselor, Sarah, when she calls to schedule a time. Here Dana describes how she feels about Sarah's attempts to visit her.

Sometimes I think why can't you just leave me alone, you know? Every time the phone rings—you know, one or two times a week. [spiritual counselor] called on Monday and said well the nurse will be there on Friday and I said I know Sarah, and she said well I'll be there on Thursday and I said no you won't. I said, come on. I have [interviewer] coming on Tuesday now you want to come on Thursday. I said I don't need spiritual help. I said can't you just leave me be for a while? You know? She said well I can rearrange my schedule and I said well I'm sorry Sarah but I just don't need all this company all of the time.

Patients' personal beliefs about dying and religious and spiritual orientation make the role of spiritual counselor particularly volatile. Some patients loved their spiritual counselor others disliked the very idea of a spiritual counselor. Visits from the spiritual counselor were often declined by patients who either expressed that they were non-religious, that they had external spiritual support (e.g. a church pastor they trusted), or that they did not want to talk about those things. The relationship with the spiritual counselor is the linchpin of its success. A skillful and tactful spiritual counselor can often approach patients in a way that makes the patient desire their visits. Dana experienced this with her first spiritual counselor, Ken, who approached Dana as a student approaching a teacher: "When I'd see Ken he'd say what are you going to teach me today? Because I've done a lot of reading for three years about life after death, and I knew a lot about heaven." Her current spiritual counselor, Sarah, asks Dana awkward questions, which she finds condescending, "... sitting here with that silly grin on her face

asking ‘why do you think you’re still here?’ Why do you think? I don’t know!’ A very independent and outspoken patient like Dana is not willing to tolerate hospice workers she finds patronizing.

A patient’s beliefs and preferences also shape the content of hospice worker visits. Spiritual counselor visits with patients involve friendly conversations, heartfelt discussions about serious issues, playing music or singing, or praying and re-creating religious services. The content of spiritual counselor visits is a combination of formal choices and the spiritual counselor’s intuition of patient preferences. For Alice, an 88 year old with Pulmonary Fibrosis living in an assisted living facility, she describes her spiritual counselor as a “minister” who brings a banjo on visits, sings to her, and keeps her company. For other patients, spiritual counselors will provide religious services or specific rituals in the comfort of their home, Gene, the 77 year old with Prostate Cancer tells me he has a powerful religious faith and complex relationship with God. Although Gene refused visits from his last spiritual counselor, his new spiritual counselor Marc has a good rapport with him and offered to perform a religious service for him, which I was fortunate to observe.

Marc’s customized service for Gene involves singing hymns (and playing them on a iPod with speakers attached), readings from the Bible, a short “sermon”, prayers, anointing with oils, and a communion ceremony complete with bread and wine. Gene is sitting in his recliner and wears sweat pants and a white undershirt with a blood stain on it from where he gave himself an injection that morning. He alternates between respectfully listening to Marc as a congregant would in a packed church and interrupting to ask questions or tell Marc how he feels. Gene is nearing the end of his illness and is

experiencing much suffering. At times Gene appears calm, at other times he becomes emotional, tears up and bends his head and cries. At one point Gene tells Marc, “You think you are prepared for this path, but you never are. I feel lonely, even when people are around. I could be in the middle of a packed football stadium and feel alone.” They talk for a while about Gene’s feelings before resuming the service. Gene trusts Marc and gives Marc access to some of his most personal thoughts. Gene appears to gather spiritual support and solace from Marc.

While a patient’s religion or spirituality has a profound impact on the experience of hospice and dying, its influence is not always predictable. A patient’s spirituality does seem to have an effect on hospice care in a direct sense. Patients who more openly talked about their religion and spirituality seemed more often to have a spiritual counselor working with them and to appreciate the visits and conversations they have with that spiritual counselor. Patients who did not identify with any religion were more likely to refuse visits from a spiritual counselor or to see them as unnecessary and burdensome.

The relationship between patients’ spirituality and experiences at the end of life is equally complicated outside of the context of hospice care. Spirituality could be a source of comfort or of additional suffering. Some patients with a strong set of religious beliefs wondered why God had abandoned them and maintained hope that a miracle would cure them.

Belief in the idea of an afterlife was a source of comfort to some patients at the end of life. Perhaps the most outspoken patient on the subject of the afterlife was Dana, the 79 year old with lung cancer, who told me she had spent years reading books about what psychics have learned about the afterlife.

Because I've done a lot of reading for three years about life after death. And I knew a lot about heaven. Oh Elly [saying my name wrong], you wouldn't believe what I know about heaven. All of the books say the same thing, the psychics you know, they all say the same thing about heaven and I can't wait to get there. You can either be an essence which is spiritual form in which you are just a blob of like clear gel or you can take physical form and have your regular body, and when you're in heaven you can turn either way. My son said, I told my son, you do this for me, let me just go up there—because he's read some of my books—my son! But he said no, no, no, I know all about heaven he said, I'll go up there, you stay here and he knows you know, he said I can't wait to go either. He said, although I like my life, you know but he knows all about heaven.

Dana points out a book called Life on the Other Side by Sylvia Browne, sitting on her coffee table with other books that appear to be about the afterlife. Beliefs or questions about the afterlife were sometimes discussed with hospice workers, from nurses, to social workers, to spiritual counselors.

Judith was another patient who believed in an afterlife and described herself as at peace with her impending death. Judith told me she hoped to be reunited in heaven with her favorite dog, Nicky, who had recently died. During our interview she recounted several stories about what she called “ghosties”, visits from deceased friends and relatives. During an observation visit between Judith and her social worker, Carolina, Judith also spoke candidly about heaven, and wondered about what it would be like, pondering, "I don't know if you drop your religious beliefs when you go to heaven." For these patients the thought of an afterlife offers hope and their spirituality provides solace.

For other patients their religion is a source of despair; they feel abandoned by a God who is not granting their prayers to be cured or have more time. These patients referred to their personal relationship with God as alternately a source of solace and a source of misgivings. Gene, the 77 year old Navy man with Prostate Cancer, in

interviews with me first spoke of God as a source of comfort to him: “Yeah, God has been wonderful to me. And I do contribute it to God... God in his mercy has extended my life to where it is today.”

However, a month and a half later, not long before his death, I witnessed a ceremony led by his spiritual counselor, Marc, in which Gene alternately appeared comforted and incredibly sad. After the ceremony outside the house Marc told me that he believed Gene had “deep spiritual pain.” Elaborating he tells me that Gene told him that he feels like, “he keeps praying and his prayers are going up and hitting the ceiling, instead of getting through to God”. In Gene’s case his declining health had contributed to his frustration that his prayers were not being heard, as he told me that his biggest wish was to have more time on earth with his wife. In addition Gene told me he felt he was cursed to have Prostate Cancer; all the men in his family had had this disease and most had died of it. In Gene’s case his spiritual beliefs made accepting the idea that he will die soon, and rejecting further medical treatment even harder for him. Similarly, many spiritual counselors described having patients who fervently prayed and sometimes believed they would experience a miracle of healing.

Even patients who do not adhere to organized religion or who do not believe in God sometimes express that they yearn for some form of spirituality at the end of life. For example, Rachel a 96 year old Jewish woman who states that she follows Jewish traditions but not religious beliefs, says to her spiritual counselor during a visit, “I wish I could be a true believer because we aren’t built to last.” Her spiritual counselor replies that she understands this feeling. Later her spiritual counselor, Lena, tells me she thinks

Rachel is reaching a point in her illness when as she declines her mortality is becoming more obvious and she uncomfortable thinking about what comes next.

Spirituality not only shapes hospice care, it shapes broader life experiences. Several of the patients I met with told me church was an important part of their lives, yet either due to decreased mobility or concerns about their immune system they no longer attended church. Some patients found ways to stay connected to a church. Charlie regularly watched Dr. Charles Stanley from the First Baptist Church in Atlanta on television. Joseph and his wife Joan were no longer able to physically attend their church after Joseph's doctors recommended he not go into public places because his immune system was weak. However, they found that their church streams their services live online, so they attend services virtually from the comfort of their home. Others like Cliff, still drive to church every Sunday toting his oxygen machine, because he values the social relationships at church.

Spirituality and religion are important factors to consider in any examination of the end of life and particularly with regards to the experience of hospice care. Not only does spirituality shapes whether a patient desires hospice care, and whether they broach spiritual and philosophical topics with hospice workers, it can also change a patient's outlook on their experiences. Judith and Dana seem comfortable and positive in their belief that they will go to heaven. In contrast, Gene's faith in God is shaken by his painful physical deterioration and he is frustrated that his prayers are "hitting the ceiling." Religion and spiritual beliefs have the potential to provide great solace or great distress.

CONCLUSION: SOCIAL CAUSES AND EFFECTS

In this chapter I have reviewed how a patient's social circumstances strongly shapes their decisions and experiences at the end of life and within the context of hospice care. In many instances I show patients making a clear formal decision about which hospice workers to meet with, or which services to use. In other cases the decision-making is less formal, but no less influential. By making their preferences and needs known patients shape their experiences in subtle ways. I examine family considerations, financial circumstances, attitudes towards dying, and religious and spiritual beliefs as strong determinants of patient choices and experiences.

Family context is perhaps the single most defining factor in the end of life experiences of patients in this study. The size and strength of family and support networks are fundamental in shaping a patient's experience. Families help patients make decisions about medical treatment and care; sometimes support patient choices, and sometimes they oppose them. Generally family members appeared to reduce patient stress by taking on many of the patients' burdens and obligations, however sometimes family members increased stress and anxiety by disagreeing with patients and causing internal strife within families. Sometimes patients' family members improved their hospice experiences since spouses or children often acted as advocates for their family member with hospice. Less commonly family members did not approve of hospice or stymied hospice workers efforts to provide more services to a patient. Strikingly patients living alone appeared to have one unexpected advantage (despite significant disadvantages) in that they could make choices about hospice services unhampered by concerns for other members of the household.

Often family considerations included the financial circumstances of the patient and their family. This study provides a case study of some of the subtle ways in which financial circumstances affect care received at the end of life. There are financial motivations and rewards for using hospice care, which were mentioned by most patients regardless of socioeconomic status. Although the hospice benefit, paid through Medicare is the same for all hospice care patients, a patient's financial assets remained influential in several pivotal ways: the use of hired caregivers to supplement or replace hospice caregivers, the ability to pay for important expenses not covered by the hospice Medicare benefit, and the ability of family members to care for a dying patient or to fly in to visit them.

Attitudes toward dying and spirituality also play an important role in whether a patient will enroll in hospice care, which hospice services they will use, and more broadly how they experience the end of life. Patients who were more willing to speak about dying and perceive themselves as dying reported easier transitions to hospice care, often they self-referred. They were also more willing to take advantage of the entire gamut of hospice services. The quality of hospice care and general life experiences at the end of life was also influenced by these attitudes. Patients who saw themselves as dying reported being more at ease, while patients like Gene and Charlie were distressed by the fact that choosing hospice meant they had to relinquish certain curative medical care.

Spirituality also strongly shaped patients experiences. It shapes discrete choices such as whether to meet with spiritual counselors, but it also shaped patients' general outlook. Prayers, belief in the afterlife, and attending church could be a powerful positive force in patients and family members lives. However, for some patients like Gene the end

of life was a time of great spiritual suffering. While God had been a source of solace to him throughout his life, he felt God had abandoned him at his time of greatest need. In this sense spirituality not only affects medical decisions, but also medical changes can precipitate changes in a person's spiritual outlook.

While this chapter focused on how social context influenced medical decisions, it also provided a glimpse into the converse: how medical decisions shaped social context. I showed how decisions about catheters and diapers could have consequences including financial hardship and overworking family member caregivers. I showed how doctor's stipulations about minimizing germ exposure in crowded places like churches could lead patients to either find creative ways to heed this advice, as in attending online church services, or patients could simply judge that their social and spiritual needs were more important than the risk of infection. These are examples of the inextricability of social and medical decisions.

As patients' illnesses progress their preferences and choices change in response. By necessity the patients enrolled in this study were still able to communicate and were often still mobile, but in many cases I watched their condition worsen. Some patients made a deliberate choice to limit their independence, although often that choice is driven by fear. Joyce and other patients described stopping driving because of concerns for their safety. Rachel, the 96 year old with Debility Unspecified, stopped going out in public because she was afraid of what might happen after she had a mini-stroke, known as a Transient Ischemic Attack (TIA), in a grocery store. At the very end of patient's lives, a time period hospice workers call "actively dying", dramatic changes in patients' health provides vivid examples of how medical decisions influence social life. As I show in the

next chapter patients and family members are faced with very specific choices with extreme social consequences. For example, whether the patient should be sedated, whether to move the patient to the hospice inpatient center, and whether to offer food and fluid. These actions all have a profound social effect. They not only change how someone dies, i.e. whether it appears peaceful and quiet to family members, they even change how long the dying process lasts as ceasing food and fluid will shorten the dying process (Pool 2004). As one social worker, Dennis, told me refusing food and fluid is a choice patients and family members must make, “Patients can refuse to eat and drink and that will speed things up, but that is their choice.” As I illustrate in the next chapter hospice workers are adroit at presenting patients with these difficult choices which both acknowledge the patient’s social context as an independent variable and a dependent variable.

This chapter is currently being prepared for submission to journals for publication. The dissertation author was the primary investigator and author of this material.

CHAPTER 5. HOSPICE WORK: HOW SOCIAL DECISION-MAKING FOSTERS PATIENT AUTONOMY

In this chapter I argue that hospice workers encourage patients to make decisions by framing many medical decisions as inherently social. In this sense hospice workers, while working within a “medical” institution, contribute to the demedicalization of dying by accentuating social concerns. While prior research emphasizes that medical institutions and professionals constrain patient autonomy, I show that the tactic of treating medical decisions as social decisions leads hospice workers to foster patient autonomy. In the first part of this chapter I explain how hospice as an institution treats medical care for dying patients as a social endeavor involving myriad social decisions. In the second part of this chapter I highlight how this attention to the social context of decision-making fosters greater patient autonomy.

My argument runs counter to a vein of sociological research which details how medical institutions are medicalizing and constrain patient choice. Instead I posit that by emphasizing social concerns, hospice care and hospice workers are a demedicalizing influence. The emphasis on social concerns is twofold: (1) hospice workers encourage patients to focus on social factors in making medical decisions, and (2) attention to holistic⁴⁰ care means hospice workers are also working directly on non-medical goals and

⁴⁰ Holistic care is defined later in this chapter using James’ understanding of holistic care as comprising “social, spiritual, psychological and financial as well as physical care.”

decisions such as those related to psychosocial coping, spirituality, and family concerns. However, even this delineation of *social* factors is too rigid, social concerns are interwoven with medical and other end of life decision-making in ways that make it difficult to draw a line between social and medical choices. The hospice workers focus on social concerns renders patients and family members the most important experts in questions of end of life care. I begin by discussing hospice's institutional features and how its emphasis on social decision-making is related to the sociological concept of demedicalization. I then show how in practice hospice workers encourage patient autonomy by regarding social concerns as equal to or sometimes more important than medical knowledge.

HOSPICE AS A DEMEDICALIZING INFLUENCE

I define a *demedicalizing influence* as a force that leads certain actors to define and treat a previously medicalized issue as less medical and more social, or even at times moral. The literature on the medicalization of human conditions explains how social or moral issues became medical, as in Conrad and Schneider's exploration of the transformation from "badness" to "sickness" (1980). However, this literature underestimates the importance of demedicalizing influences, which facilitate non-medical and social perspectives. The literature on the historical shifts in medical care in the United States is largely concerned with growing medicalization and the expanding power of the medical industrial complex (Clarke et al. 2003; Conrad 2007; Relman 1980). A

James, Nicky. 1992. "Care = organisation + physical labour + emotional labour." *Sociology of Health and Illness* 14:488-509.

similar literature on hospice care similarly accentuates bureaucratization, institutionalization, secularization, and medicalization of hospice over time (Bradshaw 1996; Fox 2010; James and Field 1992; McNamara, Waddell, and Colvin 1994; Siebold 1992). Despite some evidence to the contrary I conceptualize hospice as a demedicalizing influence. The literature on mainstream medical care suggests that institutional features constrain patient choice (Anspach 1993; Kaufman 2005; Timmermans 1999; Zussman 1992). I argue that home hospice care in the United States has distinct institutional features that make it an important counter-example to research finding increasing medicalization and constraints on patient choice. The demedicalizing influence in tandem with its emphasis on the social context of patient's lives empowers patients and families to make important decisions.

How can a medical institution such as hospice be inherently demedicalizing? As I argue in Chapter 2, Conrad's somewhat limiting definition of demedicalization suggests both medicalization and demedicalization are absolutes, while I contend that they are better conceived as opposite ends of a spectrum. Conrad defines demedicalization as, "when a problem is no longer defined as medical, and medical treatments are no longer deemed appropriate" (2007, 7). While hospice care never purported to fully demedicalize dying, it was always intended to push dying away from the most medicalized end of the spectrum and emphasize social, spiritual, psychological and other non-medical concerns. I contend that research should consider the impact of these demedicalizing influences, which Conrad labels as "resistance" or "reform" of medicalization (2007, 160).

While medical professionals are trained to respond to dying as a medical problem, families always have and always will see its social character (Lock 2002).

Demedicalizing trends such as hospice care indicate great tension within and between expert and lay points of view. Demedicalizing influences also dramatically change the experience of some forms of medical care by empowering patients as in the case of midwifery and changes in childbirth (Conrad 2007). Hospice care is a powerful example of a demedicalizing influence in which dying is treated by hospice workers not only as a biological process, but as a social process that can and should be guided by social motivations.

Looking at the demedicalizing influence of hospice provides insight into the critical question of “who” defines a problem (i.e. dying) as medical. I suggest that Conrad’s definition of medicalization is lacking a conceptualization of which actors have the power to define things as medical. Conrad says, “Medicalization describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders” (1992, 209). In examining the participants in hospice care, it quickly becomes clear that hospice workers, patients, and family members all conceive of dying as a holistic process in which medicine plays a role alongside psychological, social, and spiritual concerns. The substantive chapters of this dissertation show that different sets of actors at each stage of the dying process (before and after referral to hospice) persist in understanding hospice and end of life medical decisions as social decisions.

Much of the research on hospice care suggests that hospice has succumbed to increasing medicalization, but fails to recognize hospice care’s persistent demedicalizing influence. Some researchers assert that hospice has become part of mainstream medical care, instead of a distinct alternative to it. Siebold’s analysis focuses on hospice care in

the United States, and she is highly critical of the contemporary practice of hospice care and describes, “the transformation of hospice from a revolutionary way to help dying patients to simply another, albeit specialized, health care service with hospice overtones” (1992, 3). Siebold then uses a “stage theory of social movements” to assert that the hospice social movement has progressed from incipience to coalescence to institutionalization to fragmentation, and asserting that hospice has stopped short of the last stage “demise”. I argue below that what hospice provides as an institution is qualitatively different than other medical care. It is not a “health care service with hospice overtones” (Siebold 1992, 3), but rather I argue that it is the reverse, a hospice service with health care overtones. Below I show that hospice is fundamentally distinct from mainstream medical care because of its demedicalizing influence.

Some attempts to characterize hospice work in the United States suggest the opposite, that hospice is a medicalizing influence. In his dissertation Fox suggests hospice is medicalizing a new trait: suffering (2010). While hospitals medicalize dying, treating death as the “enemy”, Fox argues that hospices medicalize suffering treating it as the enemy. While Fox is certainly correct that the hospice movement brought the medical profession to bear on the issue of how to supply compassionate and skilled pain relief through the use of pain medication, my research reveals a holistic attitude toward suffering more in line with Cicely Saunders conceptualization of “total pain” (Clark 1999; Saunders 1996). Fox is right that hospice care entails a “suffering-as-enemy” orientation, but hospice care marshals a set of beliefs and practices to counteract suffering that are not seen as medical either by hospice workers or hospice patients. In this chapter

I elaborate on the social nature of suffering and dying and these non-medical tactics for reducing suffering and improving quality of life.

Instead of being medicalized, I argue that hospice provides a middle way, combining the advantages of mainstream medical care with the advantages of more holistic care. Pederson and Emmers-Sommer note the hybrid character of hospice by saying, “As a response to the displacement of the dying process, the hospice movement, which incorporated the best elements of the home setting and hospital medical care, emerged as a third avenue for patients and families facing terminal prognoses” (2012, 420). As this analysis suggests hospice was not intended to be a complete rejection of medical care, nor was it designed to be a perfect replication of the home/family model of care. Instead it was intended to be a hybrid institution responding to both medical and social concerns with both medical and social strategies.

James suggests model is derived from a type of caring found in family life: “This holistic model of care is an emulation of what is deemed important in, and integrated into, family life - that is social, spiritual, psychological and financial as well as physical care” (1992, 491). Yet James like others suggests that ultimately hospices are more like workplaces than like family care, saying that they are “best understood within the ideal-type of workplace health care, rather than on the model of ‘family’ care to which they aspired” (1992, 491). James shows how the institutional pressures of the inpatient hospice unit in Britain override the ability to maintain the family styled approach and family home type environment. I suggest it is problematic to base generalized assumptions about hospice care on research based in countries like the United Kingdom and Australia with predominately inpatient hospice care (Broom and Cavenagh 2011; James 1992; Lawton

2000; McNamara 2004). The structure and usage of hospice care varies widely across countries, in particular eligibility for hospice, whether curative measures are included with palliative care, how services are paid for, and the location of care vary. I contest that one critical point of difference is that in the United States hospice care typically occurs at *home* (Remington and Wakim 2010). In Chapter 4 I discuss how home hospice care changes the power balance and dynamics of encounters with hospice workers, granting patients and families more power. In the United States home hospice care is the dominant model and I argue that the home setting and other institutional features emphasizing the social nature of dying combine to foster patient autonomy.

The importance of social concerns throughout hospice work is illustrated by two related phenomena: its demedicalizing influence and its holistic care approach. Hospice care is a new type of hybrid institution combining the features of traditional medical institutions with elements of non-medical holistic care. An essential part of this “care” is an emphasis on the emotional, social, and spiritual well-being of patients and their family members. Hospice workers are skilled in emotional labor (Hochschild 1983; James 1992). They develop relationships with patients and family members and are highly attuned and responsive to their moods.

Most sociological research focuses on how hospice has become institutionalized and in some senses co-opted by mainstream medical care. It does not analyze the substantial differences between the institutionalized form of hospice care and hospice work and the more traditional medical institutions and medical work. I argue that hospice care institutionalizes demedicalizing tendencies and holistic care, both of which foster patient autonomy. By its very nature demedicalization lends to seeing dying as a holistic

illness experience, not a biological progression of disease. In the case of hospice patients the shift from focusing on curing disease to caring for a person with illness leads to an increase in patient autonomy. In the pursuit of curing disease doctors are the authorities if not wholly deciding then often guiding decisions. However, illness is an inherently most personal and subjective experience (Kleinman 1988), and as such the patient and family are typically the best position to know what changes in care will benefit them. Caring, and improving the quality of care, requires attention to quality of life, something patients can best define for themselves. In this chapter I show how patients are prompted by hospice workers to think about their preferences and communicate their desires for care. The distinct institutional structure of hospice care and the day-to-day interactions of hospice work further patient autonomy by focusing on the social nature of medical care decisions.

INSTITUTIONALIZATION OF SOCIAL DECISIONS

Pacific Hospice as an institution and hospice workers as a group are structured in such a way that they conceptualize medical decisions as social decisions. The structure of the institution itself is a demedicalizing influence in three distinct ways: (1) the hospice workers embody demedicalization, (2) hospice workers emphasize the social nature of medical decisions, (3) hospice workers promote holistic care focused on social well being. In these three ways hospice as an institution frames many end of life decisions as not exclusively medical. The choices I observed patients facing rarely required medical expertise or technical knowledge, instead they involved a weighing of

personal beliefs and family circumstances. Hospice and hospice workers understanding of medical decisions as social decisions arises from a broad understanding of dying itself as a social process. It is this attention to the illness experience associated with terminal illness that enables hospice workers to translate the same focus on social concerns to questions of how to make decisions and who makes decisions.

Hospice Workers

In this study hospice workers embody the philosophy of demedicalization, rejecting the medicalization of dying and embracing the idea of dying as a social process and a normal stage of life. Hospice workers come from a variety of non-medical backgrounds and the majority of hospice workers do not have medical training. Even the medical professionals working for hospice such as nurses, tend to see themselves as rejecting mainstream medicine's approach to dying, and adopting a more holistic and humane mode care.

The occupational structure and hierarchy of Pacific Hospice furthers the idea of medicalization by downplaying the medical aspects of dying relative to mainstream medical care. Hospice care's interdisciplinary teams include doctors, nurses, social workers, spiritual counselors, home health aides, grief counselors, volunteers, and the patient and the patient's family. NHPCO estimates on the distribution of paid staff within hospice show that only 2.9% of paid hospice staff are physicians, while 4.3% are bereavement (grief) counselors, 4.3% are chaplains (also known as spiritual counselors), 8.6% are social workers, 18.8% are home health aides, 38.0% are nurses, and 21.3% are

administrative⁴¹ (National Hospice and Palliative Care Organization 2012) (See Table 5.1). The hospice workers who regularly visit patients and family at home at Pacific Hospice are the nurses, social workers, spiritual counselors, home health aides, and volunteers. While physicians have a prominent role to play within hospice care⁴², at Pacific Hospice physicians have relatively few interactions with patients using home hospice care.

Table 5.1 Distribution of Paid Staff – Hospice Care in the U.S. in 2011

Nursing	38.0%	Other Clinical Staff	1.9%
Non-Clinical/Administrative	21.3%	Bereavement Staff	4.3%
Home Health Aides	18.8%	Chaplains	4.3%
Social Services	8.6%	Physicians	2.9%
Estimates from National Hospice and Palliative Care Organization 2011 Data Collection			

The organization of the interdisciplinary team also furthers the idea of demedicalizing dying. Even though all of the hospice staff is employed by a medical entity, many of them are not “medical” professionals or have no training in medicine. Social workers, spiritual counselors, and grief or bereavement counselors are important examples. Home health aides at hospice are mainly concerned with helping patients with bathing and personal hygiene and do not perform any medical treatments. Hospice

⁴¹ A further 2.0% are classified as “other clinical” workers, and 0.4% are Nurse Practitioners.

⁴² Physicians of course still oversee and sanction medical treatments and medications, and consult with hospice staff about a range of issues. However, since physicians rarely go visit hospice patients at home, they rely upon the other hospice workers to do the bulk of the hands-on work and to raise treatment concerns at weekly meetings or on as needed basis. While the physician is still considered the mainstay of hospital and clinical medicine, home hospice work is centered on the work of nurses, social workers, home health aides, spiritual counselors, and volunteers.

volunteers⁴³ are an important contingent of hospice workers and their work is mainly providing social companionship and respite to caregivers. The very idea of an interdisciplinary team, as hospice defines the concept, means that a range of professions and backgrounds are relevant to the experience of the dying patient⁴⁴. Even nurses do not limit their work or interactions with patients to medical issues, often addressing social, psychological, spiritual, financial, and other issues with patients. Dying is addressed as a holistic experience, not as merely a disease process.

It is not only the different occupational hierarchy, but also the different work environment that leads to a demedicalization of dying. Because hospice workers visit patients in their homes, often over the course of weeks or months, they develop strong personal relationships with patients and family members. They also see patients as not simply medical patients, but individuals with needs and concerns that often override medical issues. Here a hospice nurse, Ellen, describes how the home environment makes a big difference to hospice care.

And I think that was the other thing I learned early on was, that is huge, is that you are a guest in their home, no matter what you're there for, and this is their journey, not yours. Because I've worked with people and they're like, oh they come right in, oh you need a bed, we can put it here, dah, dah, dah, this, that and the other. And it's like no, they may have been married 60 years, and they don't want to be apart, and I'm sorry it's a little difficult to bathe them in bed, but for assessing or whatever. I don't know or that you think it would be easier for the family, I mean of course, always offer and everything, but you have to respect the whole picture for

⁴³ Hospice care has a strong history of volunteerism. The NHPCO estimates for 2010 show 458,000 hospice volunteers provided 21 million hours of service. National Hospice and Palliative Care Organization. 2011. "NHPCO Facts and Figures: Hospice Care in America."

⁴⁴ Pacific Hospice interdisciplinary teams are not managed by nurses, instead team managers supervise several teams. Likewise the team itself shares responsibility equally, with all team members participating in duties like being the on-call person for the day.

people, not just for yourself. And that this is their journey, not yours.

Ellen describes how a nurse might jump to the conclusion that a patient needs a hospital bed, but understanding the family dynamic would lead this nurse to agree that what is most important to the patient might be continuing to sleep in a shared bed with a spouse. Even if bathing the patient would then be more difficult for them, hospice workers approach these issues from the question of what is important to the patient, not what would make medical care easier or better. Seeing patients in the home setting is conducive to developing an understanding of the patient not just as a patient, but also as a person living within an important social context.

Hospice workers also see themselves as a demedicalizing influence making dying more humane, reducing invasive medical treatments, and providing a form of caregiving absent in mainstream medical care. Hospice workers actively foster the idea that they are different than typical medical professionals and many describe themselves as “caregivers”. The majority of hospice workers are female and many describe caregiving and nurturing as female traits. In this study 85% of hospice workers participating were female and hospice workers told me these trends generally held for the larger population of hospice workers⁴⁵. Indeed the work of caregiving itself in our society, whether it be for children or the elderly, is historically and culturally seen as the province of women (England 2005; Hochschild and Machung 1989). Focusing on their role as caregivers,

⁴⁵ The nursing profession has been historically female, as has social work in the United States. Spiritual counselors seem to be more evenly split between the genders, perhaps because until recent times in Judeo-Christian religions the religious authority structure was typically filled by men. Hospice volunteers are also a majority female, many of them older women who do this work in their retirement or after losing their own husband or other relatives.

rather than as medical professionals, is another way of demonstrating that hospice patients and their family members are treating dying as a holistic process during which their primary concern is caring, which includes but is by no means limited to medical care. Instead caring is a combination of various holistic concerns including medical, administrative, psychological, social, and spiritual needs.

Many hospice workers describe being drawn to hospice work following negative experiences working in hospitals and nursing homes. Several hospice nurses explicitly told me that choosing hospice work was a consequence of their rejection of the medicalized way that mainstream medical care treats dying patients. Here a hospice nurse, Penny, describes how she was disturbed by witnessing patients dying alone in hospitals, and how she reacted to this issue and ultimately became a hospice nurse:

But, I would see people passing and it would just break my heart and then, this one person, I just kind of made sure all my other people were okay. I had five patients that night and I went in and held her hand. She was a nun. I just said, you served God all these years, you're not dying alone and I went in and turned on the music for her. Somebody had brought in some gospel music. Turned it on. She was just like hanging there, you could tell. Her heart rate was really low. Her blood pressure was low. I think it went down to 40. I just said, you're—I could tell, she was not even opening her eyes. She was unresponsive. But I just went in and said—every time I'd go in, I'd say, I'm Penny, I'm your nurse. I'm just checking on you. I'm going to go give everybody their medication and then I'm going to come back. Once I did all that. I brought all my charting in her room and I said, I'm sitting right here, I want you to know I'm by your side. You're not dying alone. It's okay to go. It's okay to let go. I sat down and like started to chart and she was gone in five minutes. I thought, look at the power of this. You know, it's going to make me cry telling you this.

For Penny and other nurses they described feeling like their primary responsibilities in nursing homes and hospitals were filling out paperwork and administering medications and they did not have the time to provide real comfort and

solace to their patients. One nurse, Eva, describes her time working in a nursing home as predominately “pushing pills”, and not *caring* for patients. These nurses and other hospice workers see hospice as a rejection of this impersonal and medicalized approach to dying, and as allowing them to see their patients as a “whole person” and address their many needs.

Day to Day Hospice Work

It is not only the institutional structure of home hospice work that diminishes the medicalization of dying, but the content of hospice work. Hospice workers actively try to reduce the use of invasive medical treatments and diminish what they see as overtreatment. This tendency does not mean that hospice workers are anti-medicine. On the contrary they actively work to ensure patients receive ample pain medication and treatment for various symptoms in the tradition of palliative care. But they often actively try to dissuade patients from medical interventions that they view as unnecessary. This demedicalization of the medical care within hospice has twin motivations, first many hospice workers view certain interventions as ineffective, second they view these interventions as actually harmful to patients, most commonly because of the physical and psychological exertion required by patients.

In several instances I observed hospice staff trying to gently convince hospice patients to turn down extra medical tests and procedures community physicians recommended. They did this by questioning the patients' motives for seeking this extra medical care and encouraging the patient to reflect on what purpose the extra care would

serve and what social costs it might include. In one example Gene, a 77 year old with prostate cancer, tells his nurse Stacey that he is going to see a cardiologist for an echocardiogram. Stacey asks him, “What is the goal of getting the test?” Gene replies his doctor wants to find out if his heart problem is contributing to his shortness of breath. Stacey replies, “doctors like to have as much information as possible, so they send you for lots of tests. Doctors get on this bandwagon of getting lots of different tests.” Stacey then gently tries to explain to Gene that even if the doctors find out what is causing the shortness of breath they will not be able to fix the problem due to his many other health issues. Gene who has often complained about how exhausting and physically demanding it is for him to go to medical appointments seems to be weighing the pros and cons of the echocardiogram at the end of this nursing visit. Here we see that the hospice nurse's role is not only to ensure patients receive necessary medical care, but also to educate patients about the possible benefits of limiting certain medical interventions.

In other cases demedicalization is not about reducing medical interventions, but instead about reframing them as driven by social concerns. In a typical example hospice workers might encourage patients to assess the social causes and effects of medical interventions. The topic of palliative sedation is an apt example. Palliative sedation is defined by administering increased pain medication as death approaches in order to suppress pain and agitation, but it also has the side effect of rendering many patients lethargic, unable to communicate, or unconscious. Palliative sedation is often influenced by social factors; patients and family members do not want the patient to be pained, frantic, or unmanageable during their last hours or days. A hospice nurse, Stacey, tells me

she presents patients with this socio-medico choice prior to their death and discusses the trade off it involves it with families.

And it's a good idea to ask that patient, if you get that opportunity to ask them "how do you want to be treated for pain? What's more important to you, having as much pain management as possible and dealing with the side effects, sedation, over sedation, or do you want your pain just kind of marginally controlled, so you can be very conscious?" Maybe they want to be conscious and present for their family as much as possible... And I've had patients tell me point blank what they want, or there are like some people may be worried about getting confused and loony, and they don't want to be like that around or towards their family. One patient said he had a friend who died and such and such, and it had gone to his brain and he had been just the most impeccably kind person his whole life, and in the last days of his life, he was like shouting obscenities at his wife, and he goes, "my God, don't let me do that." He goes, "I am counting on you to – don't let me do that, you know, when I'm going, give me drugs so I don't do that."

In this example it is clear that this medical intervention can be motivated by social concerns and hospice workers encourage patients to think about it as a social decision.

While a medicalized notion of dying and pain might treat the relief of pain as the primary objective, this hospice worker encourages her patient to think about social considerations.

While these examples concern how hospice workers can encourage demedicalization even through the discussion of medical interventions, hospice care is also holistic in nature and much of the "work" of hospice care is not medical in nature.

HOLISTIC CARE AS A DEMEDICALIZING INFLUENCE

In the above examples I showed how hospice is a demedicalizing influence on dying by minimizing both medical interventions and medical definitions for those interventions. Hospice care is also demedicalizing in the sense that it includes under its

umbrella of care many tasks that are essentially non-medical and are instead directed at improving patients and family members psychological, social, and spiritual well being. Among these tasks includes the large swath of hospice work that involves preparing patients for death in various ways. The provision of holistic care by hospice workers provides a compelling case study of the difficulty drawing a distinction between medical care and social care, or medical decisions and social decisions.

Hospice work involves holistic care for suffering, or what Cicely Saunders conceptualized as “total pain”: the social, psychological, and spiritual causes and manifestation of suffering (Clark 1999; Saunders 1996). Saunders’ development of the concept of total pain suggests a demedicalizing perspective on dying since there can be non-biological sources of sufferings (i.e. spiritual pain). The concept of total pain provides a radical entangling of medical and non-medical concerns, suggesting that social concerns such as problems with one’s family may actually be a source of or exacerbate physical pain. Hospice’s inclusion of a breadth of professionals and practices such as spiritual counseling, grief counseling, social workers, and volunteers, providing a range of services from companionship to Reiki and energy healing, are indicators that suffering like dying is treated as a holistic phenomenon. Again a critic might insist upon even these being examples of medicalization because they are under the aegis of hospice and paid for and regulated by health care organizations. However, I show that hospice workers, patient, and family members do not define these as medical interventions.

Holistic care focuses on the whole person, not merely their biological disease processes. Discussing holistic care in the context of hospice care Pederson and Emmers-Sommer define and discuss a range of activities that would be termed holistic.

Holistic care is a health care approach in which patients are offered “complementary therapies [that] introduce philosophies and methods of health care that promote *whole-person care*” (Benor, 1999, p. 1, italics added for emphasis) To maintain this integrated type of care, hospice interdisciplinary team members offer “expert medical care, pain management, and emotional and spiritual support expressly tailored to the person’s needs and wishes” (National Hospice and Palliative Care Organization, 2008, 1). As a result, hospice patients can choose from such services as aromatherapy, massage therapy, pet therapy, music therapy, spiritual counseling, support groups, and respite care to best meet patients’ end-of-life needs. (Pederson and Emmers-Sommer 2012, 420)

While Pederson and Emmers-Sommer emphasize that holistic care treats the whole person, in their sample of 10 home hospice care patients in the United States they largely found that hospice patients focused on their impending death as the key feature of hospice care, not its holistic approach. Their research finds relatively little understanding of what holistic care means among patients and few patients describe receiving holistic care⁴⁶. However, in my sample there was ample evidence of the importance of holistic care to patients, both in the narratives of patients and in more obviously in my observation of how hospice workers interacted with patients.

Hospice care involves a range of non-medical work including spiritual counseling, home health aides to assist with bathing, social workers working with patients on administrative and financial tasks, grief counseling, respite care (short term care for patients in facilities intended to give caregivers a break), volunteers providing companionship and caregiver relief, and more specific volunteer services such as massage therapy, Reiki, energy healing, aromatherapy, pet therapy, hair cuts, pet care,

⁴⁶ I suggest that their dependence on interviews to uncover holistic care is itself problematic since patients may not understand the relevance of the term “holistic”, and they may not recognize when care crosses the line from medical to holistic.

etc. All of these tasks are oriented toward the patient or family members general well being and comfort. Even medical professionals like nurses spend a large part of their time meeting with patients discussing social, psychological or spiritual concerns, all part of holistic care. Much of holistic care centers on preparing patients for declining health and death. Hospice workers refer to this goal as “socializing patients to dying” or “normalizing dying”; they encourage a demedicalizing approach to dying by encouraging a view of it as something that is natural, normal, and expected.

Normalizing Dying

Much of the work hospice workers engage in involves explaining to patients and families that what they are experiencing is a normal or “natural” part of the process of dying. They encourage patients and family members to see dying not as a medical emergency, but as a gradual and normal life process. Here a social worker, Megan, describes how she views the role of hospice workers.

I think what we provide is reassurance. Just a lot reassurance and education and that’s so critical at the end because there’s so many physical changes that go on in a person’s body at the end. And I think that having us kind of as—not really “experts” but to at least let the family know, this is natural, this is what’s supposed to happen, or these are things that we can do to help this natural symptom that’s occurring. So, we give them that reassurance that they really need. Otherwise it’s totally scary. And we have—we even have family members that are really kind of hesitant to call us and then they’re just like—you know, I talked to them and they’re like, I just felt so scared, so lost. You know, I just say, you need to call us when you’re feeling like that because that’s what we’re here for. That’s another just part of my role is just to encourage them to accept us and to let us help them.

Megan uses the word “natural” to convey that what patients are experiencing is not cause for alarm nor is it unexpected. By encouraging a view of dying as normal and natural hospice workers oppose the more medicalized view of dying as a failure or defeat. Megan, a social worker, is working on an essentially non-medical task, easing patients' fears and providing reassurance. As the above quote illustrates her concern is with the whole person, not with the relatively limited issue of alleviating physical symptoms.

Hospice workers also work with patient's family members, socializing them to the “natural” dying process. I observed one nurse, Stacey, having a conversation with Gene's granddaughter who was upset that he was spending so much time in bed. Gene's granddaughter felt if he got out of bed and walked around more he would grow stronger. Stacey explained to her that at this stage in Gene's illness exertion like that would only make him exhausted more quickly, and that it was normal for him to want to spend more and more time in bed. In this way Stacey counters conventional ideas about “fighting” illness and regaining strength, and stresses that it is normal for dying patients to grow weaker and withdraw to bed. She educates patients and family members about the natural decline in health and energy that accompanies dying.

One hospice nurse, Eva, was particularly deft at combining medical care with more holistic concerns such as helping patients prepare for dying. On one visit to see, Steve, the 71 year old with lung cancer, she introduced the general topic of dying several times in subtle ways. First Eva asked about Steve's cat, which he has owned for fourteen years and who now has cancerous tumors and is dying. From her history with this patient she knows he feels deeply about the cat and that it makes him think about his own future. Steve responds saying, “I see parallels between him and me, as the tumors progress. I

wonder who will succumb to it first.” Eva sympathizes with him and they discuss the cat and Steve's fears about dying.

Nurses have a unique opportunity to normalize dying because of the constant references to physical decline in their conversations. While much of the information Eva was providing was medical the conversation often turned to non-medical issues. In one instance Steve asked Eva what would happen to his wedding ring when he was cremated, and Eva responded with advice and stories about how other patients handle the issue of what to wear or remove before cremation. Steve also discussed his will with Eva and how plans to distribute his money and his music collection. Steve clearly relies on Eva for more than medical expertise, she is also a confidant and advisor about a range of pragmatic and psychosocial concerns about the process of dying. Below I turn to the many non-medical tasks that reinforce hospice care's demedicalizing influence: hospice work that is oriented toward social, emotional, spiritual, and administrative issues.

Unfinished Business: Social, Emotional, Spiritual and Administrative Work

Much of the holistic care provided by hospice addresses patients and families' social, emotional, spiritual, administrative and pragmatic needs. As a blanket term several hospice workers referred to these topics as “unfinished business”. The term unfinished business encompasses the broad array of activities patients and family members want to address when they learn they are running out of time: making wills and other financial arrangements, arranging mortuary and funeral services, reconciling relationships, seeking closure, and saying-good-byes. One hospice nurse, Ellen, called this part of the process

“tying up loose ends.” While much of this unfinished business involves pragmatic administrative tasks, for example making a will, or planning a funeral, much of it involves psychological or social preparation for dying.

Hospice workers encourage both patients and their family members to prepare socially and psychologically for death. Related tasks include saying good-byes, seeking closure, and reconciling relationships. Hospice workers are often able to facilitate patients and family members saying good-bye. Sometimes these good-byes are planned, and sometimes like in this case described by Lena, a social worker, they are spontaneous. Here Lena describes her first time witnessing the death of a patient, a situation where a patient fell down at home and members of the hospice team came to check her after the fall and watched her condition rapidly deteriorate during their visit.

So I am on the phone with the doctor, and when I came back in the room her color had just totally changed. And it was like, oh my goodness; it was like there was nothing that could have prepared me for that. And I am just instinctually getting on the phone with the daughter and saying your mom is going, I mean I don't know what words I used, but to tell her that would you like to say goodbye to your mom. And I was holding the phone to the patient's ear and she was not responsive. But I'm passing a message to her mom, and I swear her mom passed within minutes after the phone [call], she was gone.

In this case the hospice worker placed a phone call that allowed a daughter to say good-bye to her mother. Hospice staff can often predict when a patient reaches the final stage dying, which they dub “actively dying”, and this is when they suggest to family members that it would be a good time to say good-bye. Eva describes how she facilitates families saying good-bye to patients who are at this stage.

And I said, well there are certain signs that you see. So you tell the family, you say, you know what there are some changes going on here. I don't

know what I'm seeing, this is what I'm seeing right now but it could go either way, but honestly I think we're talking about hours to days. And some people are really shocked to hear that, and they'll say really, hours to days? And I say yeah, I really wouldn't be surprised if he dies within a couple of hours, he may go a couple of days, maybe up to a week. I don't see this going on for a couple of months. And that brings it into perspective.

And you know you always tell people, you know you may want to call your family who is out of town, sooner rather than later. And some people who have issues with their families will say, well I don't want so and so to come, and I don't want, da da da. It's like look, I'm going to tell you this from experience, because I hear this a lot, you just tell them, if you don't want to call them I can call them for you. And say look, I'm the nurse this is what I'm seeing, here are the changes, and give them options. Because then later it becomes, oh I shoulda coulda woulda. And you can't take that back. If your mom, dad, husband, wife, whatever, is going to move on and you're going to be left with that guilt. And you're going to be, oh if I would have called my brother sooner he could have been here for this, oh I should have done this, you can't rewind it. What's done is done, you can't go back. And then you are going to feel guilty, oh if I would have called him I wouldn't feel, or he would have been here and da da da da da, whatever.

This excerpt is a compelling example of the social and psychological work that nurses perform. By telling family members that a patient is actively dying Eva is both preparing them for the imminent death, and giving them an opportunity to call in other family members. Like other hospice workers, Eva told me stories of patients who appeared to be hanging on until a loved one could make one last visit or say good-bye. Enabling patients and family members to say good-byes is not only an example of holistic care provided by hospice workers, but also an example of how concern for family members is a paramount concern of hospice work.

Volunteers are also often instrumental in helping patients seek “closure”. One volunteer, Harold, recalls a patient who he drove all over the county visiting places that

were important to him for one last look. Harold told me during an interview that at some point during his time working with each patient he asks him or her “Do you have any regrets in your life?” Harold is trying to facilitate closure for patients by allowing them to think about and discuss anything in their lives that needs to be addressed before dying. Another volunteer, Rob, who was a psychologist during his professional career, says one of the most important tasks patients work on is “seeking forgiveness”, which he made sure to tell me includes “the most difficult kind of forgiveness: self-forgiveness.” The strong relationships many hospice patients have with their hospice workers, and the lengthy and unrushed conversations they often have allow patients a chance to reflect upon and decide if and how to tackle these psychosocial aspects of dying.

Spiritual counselors also play a special role in helping patients or their family members find peace before death, which includes such tasks as reconciling relationships with family members and in some cases with God. Spiritual counselors told me that their work is based around the idea that there are different types of spiritual suffering that people experience at the end of life. Gloria, a spiritual counselor explains how hospice work has led her to redefine her notion of healing. Gloria describes her hospice work as promoting healing.

Well, we’re talking spiritual healing. I’m talking spiritual healing. There’s much that goes on spiritually, emotionally and socially at end-of-life with the patient, with the identified patient and with the family. There’s just...you don’t know the whole picture. You don’t know everything that’s happening in the hearts, minds, and souls of the people you interact with but it’s a time of mighty work and we’re talking about a major life crises to die or to lose a loved one is a major life crises and it’s just a rich, rich opportunity to face demons—I’m not talking about literal demons—I’m talking about internal demons that have never been faced. To be reconciled to loved ones. To be reconciled to the divine. Be reconciled with your own memories, your own past. It’s a time to find peace.

Hopefully, it's a time that you find peace so that you can die in peace and not in spiritual agony.

Describing their jobs to me spiritual counselors explain that most of what they do is simple conversation, and for some patients who are unable to communicate they simply spend time in the patient's presence, sometimes holding hands, sometimes playing music or reading from a favorite book, or sometimes simply sitting. Hospice workers stressed that "presence" was itself beneficial to patients and their family members. The presence of hospice workers gives the patients and family members companionship and comfort, even when that companionship does not involve dialogue.

For patients who are able to communicate spiritual counselors provide them with conversation that can range from the deeply personal to the philosophical or theological, and they also sometimes provide religious ceremonies or prayer. Spiritual counselors respond to patients' fears and affirm their hopes, whether that is to be cured of cancer or to die. A hospice spiritual counselor, Marc, describes how he tries to affirm patients' hopes while staying attuned to the language they are comfortable using to discuss death and dying.

And it's the same thing with the word death. If they're talking about "going" that's what they're comfortable with. I have one patient who says, "When I go to the condo." The "condo," That's what she calls it. And she's about to turn 100 and wants to die so bad but is not dying. She may not even be a fit for Hospice. It's the worst thing in the world. So one patient says pray for me that I be cured of cancer and be healed, and this patient says pray for me that I die. So I pray for her and I say, you know, God, take her to the condo right away, and she's, you know, she's crying because it's so meaningful to have that validated and affirmed for her. But you know, that's her language so it's...

This sensitivity to patient's individual needs and to their preferences for communicating is again an important part of holistic care at the end of life. Not only does care require consideration of patients and family members psychological, social, and spiritual concerns, but it requires attention to when and how they want to discuss these concerns.

Hospice workers also encourage patients to make preparations for death that concern administrative, legal and financial planning, and other pragmatic concerns. This non-medical work stresses how dying is a process that impacts all arenas of life. Financial concerns may lead hospice patients to consider moving to a facility at some point during the progression of their illness. These moves are often explicitly linked to declining health and in this example we see how they can precipitate death. I witnessed Charlie discussing with his social worker the possibility of moving his wife Mary (also a Pacific Hospice patient), whose Alzheimer's is worsening, to a board and care facility since his family is running out of money to pay for a privately hired caregiver. This financial decision is simultaneously a medical decision, which may change his wife's prognosis. Charlie tells his social worker, Megan, "I don't think Mom will last long in the home" (sometimes Charlie referred to his wife as "Mom"). Megan replied, "Maybe not, that might be what it takes for her to..." and then paused. I imagined she was going to say, "let go". Charlie responds "if not for Rhonda [the hired caregiver], Mary would be gone already." Charlie chose not to further address the question of his wife's dying, but it was clearly communicated that both he and Megan agreed that perhaps transitioning to a board and care facility will speed her dying. Hospice workers help patients explore their financial options and the ramifications of those choices.

Hospice workers often encourage patients to make administrative preparations. Several patients told me they had detailed lists of how to distribute their belongings to family and friends following their death. During a visit between Cliff and his volunteer Harold the two were looking at Cliff's old high school yearbooks as Cliff relived childhood memories. Cliff asked Harold, "What should I do with the yearbooks after I am gone, when I'm in heaven?" Cliff says he does not have any family who would want them and proceeds to say that his niece only wants money. Harold jokes that perhaps if Cliff put money in between the pages of the yearbook his niece would want them. Then on a more serious note Harold suggests that Cliff could find out whether Cliff's high school would want the yearbooks for their library. Cliff seems to take this suggestion to heart and the two continue to discuss what Cliff plans to do with his belongings. Harold asks Cliff what he will do with the big RV in his driveway and Cliff tells us he is leaving it to his hired caregiver. In this interchange we see both Cliff seeking advice and Harold asking Cliff about other preparations. In this way the volunteer Harold, responding to Cliff's cues encourages Cliff and assists him in planning what to do with his belongings.

Hospice workers also encourage patients and families to settle what they term "final arrangements", mortuary and funeral services. It is the responsibility of the social worker to bring up the topic of final arrangements with patients and family members. One social worker, Kathy, describes how she negotiates this difficult topic and encourages patients and family members to plan ahead and make choices as soon as they are comfortable.

I encourage them, like one I saw earlier today, he's just been on service for about a week, so I asked his wife about final arrangements. That is one of the big things that we work on. So she says, oh no we kind of know what

he wants. So I asked, have you made any progress toward choosing a mortuary? She said, oh no. Well I said, and I always say, it's much easier to do it now than later, because then you are in a scramble and you make rushed decisions. And I was just telling them to check in with friends and people that you know that have had good experiences. Because we can't, any of these things, in home care agencies, mortuaries, we cannot refer them to one specifically. We have to give them options. So we have a list of places that we offer.

Kathy describes this as a difficult part of her job and says that even though she's done it many times "I always have to think about the words I'm going to say," when discussing final arrangements. She says hospice patients run the gamut, from those that have had final arrangements settled for years to those patients who never get around to doing it. As with other aspects of hospice work, Kathy says she tries to "normalize" making final arrangements, stressing that it is something most people like to do ahead of time, and that doing so will be less stressful than facing difficult decisions after a loved one has died. Encouraging patients and family members to deal with these administrative and pragmatic concerns is another way in which hospice care stresses the holistic experience of dying.

In the sections above I explain how hospice workers encourage a demedicalizing perspective on dying, emphasizing social concerns and the intermingling of medical and social decisions. I show that a large part of hospice work is not about medical treatments per se. The emphasis of hospice care is on patients and family members' illness experience not just their underlying disease. Holistic care makes sense as an approach to improving the illness experience, since it attends to the pragmatic, psychological, social, and spiritual concerns faced at the end of life. The above examples make clear that providing holistic care is not formulaic, but relies on an understanding of the individual

patients, their preferences, and their personalities. In other words holistic care requires patients to take a more active role in steering the type of care they receive and the content of that care, and it requires that hospice workers stay attuned to the many differences between patients. The focus on demedicalizing care and holistic care then naturally segue into encouraging further patient autonomy by trying to discover patient preferences and abide by them.

ENCOURAGING PATIENT AUTONOMY

The above examples offer a glimpse of how hospice work facilitates patient autonomy. The institutional structure of hospice care both formally and informally acknowledges that patients can and should have an active role in determining what care they receive. Patients and family members have a prominent place in the formal hierarchy of hospice care. Care is provided by “teams” and NHPCO literature and brochures shows the patients at center of the circle or at the head of the team (National Hospice and Palliative Care Organization 2011, 3). In hospitals and doctors’ offices patients’ experiences are largely managed and controlled by medical professionals. In home hospice care patients are in their own domain, the home, and they often control when, why, and even how the hospice care encounters proceed.

Hospice workers encourage patients to make choices both through formal mechanisms hospice puts in place and through their informal dialogue with patients and families. Hospice workers regularly present patients and family members with options that they did not know existed. These options range from basic optional services, such as

seeing a spiritual counselor, grief counselor, or volunteer, to very specific treatment decisions such as palliative sedation. Very often the discussions hospice workers have with patients and the choices they present to them are not directly medical. In this sense I argue that the primary task of hospice workers is “caring” and the “medical” work, although a priority is always a subset of the larger task of caring. Because caring requires knowing what patients value and prioritize, caring fosters patient autonomy.

Understanding and acting upon patient preferences is a prerequisite for good care.

Hospice workers profess to prize the patient-centered paradigm and in this study there were several examples of how a patient’s wishes are prioritized even if doing so leads to a death that hospice workers might deem as undesirable.

Pacific Hospice formal institutional practices foster patient autonomy by providing patients with resources that help them plan ahead and make decisions. Sandra, the wife of Henri the 77 year old physician with liver cancer, described how Pacific Hospice provides a thick binder to all new patients containing carefully organized information on all aspects of hospice as well as death and dying. Several patients mentioned to me how helpful it was to have this binder at their fingertips. There is a section in the binder on making final arrangements. In this excerpt from my field notes Sandra explain how enrolling in hospice and receiving this binder prompted action (field notes 9/12/2011).

Sandra says she wanted to tell me about the binder that hospice gives patients and how helpful it has been to them. She says that they had been meaning to make plans (for a funeral) for a long time, but she says she is not sure whether it was starting hospice, and knowing what that meant, or getting this binder that made it easier to arrange everything. She said previously Henri thought he wanted to be cremated, but they went to see a BodyWorlds exhibit at Museum of Natural History and he decided to look

into that.

After doing some research and discussing it with his family Henri did decide to donate his body to the BodyWorlds exhibit, a decision he described to me with enthusiasm. The symbolic meaning of beginning hospice care prompted Henri and Sandra to recognize that Henri's death was approaching, but the tangible resource of the binder helped them to recognize what choices they faced and to take action.

Hospice workers also encourage patient autonomy through their daily interactions in patient's homes. Stacey, a hospice nurse, provides another example of the choices hospice workers might present to patients, discussing a case in which a patient was facing a trade-off between a longer life and a more painful death, and how a hospice doctor suggested presenting him with a choice.

...he was dying of colorectal cancer. And his liver, wait a minute, his kidneys were failing and he was getting dialysis. And the dialysis obviously was prolonging his life. The doctor pointed out to me, one of our palliative doctors, that colorectal cancer is a very painful, very painful way to die. And if I were that patient, this doctor said, I would rather die in toxicity from kidney shutdown than die of colorectal cancer, and so you may want to present it to your patient as an option to stop dialysis, so they can have a better death.

In this case Stacey told me the patient died quickly of a stroke before they had this conversation, but she provided it as an example of the difficult choices hospice workers may present to patients. Hospice workers facilitate these decisions by discussing a patient's options before a crisis occurs, and educating patients and family members about what to expect as death approaches. As in other examples this choice is not presented as a medical decision to be evaluated based on technical knowledge, instead it is a personal

choice in which a patient must weigh a possibly longer but more painful life against a shorter life with a less painful death.

Another way that hospice workers encourage patient autonomy is by repeatedly offering patients information and giving them the opportunity to ask questions or express their preferences. Hospice requires that staff ask patients about pain, needed supplies, medication, and bowel movements on each home visit. Hospice workers provide patients with as much information as possible, because it both alleviates doubt and uncertainty and it helps patients and family members make practical decisions. Henri, the emergency room physician, and his wife Sandra, saw this ability of hospice to set your expectations and prepare you for what lay ahead as a big advantage of hospice. As Sandra recounted, it was harrowing not knowing what to expect during chemotherapy treatments for cancer, and that uncertainty is something hospice works to eradicate.

When Henri started the second chemo, I wanted to know what we were expecting. He would let me go, you know he was getting six cycles of chemo, he would let me go with him for the first one. And so I could get the information from the oncology nurse. I mean the doctor doesn't tell you, I mean he just tells you you're going to get these three drugs in an IV, but he's not going to tell you what it's going to be like to experience getting those drugs. So we inquired about the side effects of the second one, and it was almost guaranteed that he would have diarrhea or whatever. I want to be prepared before I bring him home. So I want things at home that will take care of a need that he might have. Not go get the chemo, have explosive diarrhea, and have him be absolutely miserable and say well gee just hang on while I run down to the store and get an - you know? So that's what I see hospice does that function to the nth degree. They've really got it figured out what are the physical needs, what are the mental, emotional and spiritual needs, and not just of the patient, but of the family. And they offer, and the remarkable thing is that they offer it repeatedly. They don't expect you to remember. And they don't come from the financial bottom line thing. What's the least we can give?

Sandra finds it remarkable that hospice offers information to her repeatedly, before a problem occurs, and with the intention of helping her to be prepared for all eventualities. Being prepared itself helps patients and family members cope.

The daily interaction between hospice workers and patients encourages patients and family members to make informed decisions in both direct and subtle ways. A more direct choice includes how one nurse, Stacey, told me she reviewed patients' options for palliative sedation with them, including the trade off between being alert and possibly being in pain, then asked them to make a choice. As an example of the more subtle ways that hospice workers encourage autonomy I showed how Eva engaged Steve in a general discussion about his dying and introduced topics that allowed him to voice his concerns and questions, as he did by asking her what to do with his wedding ring when he was cremated. As these examples reveal patient autonomy within the sphere of hospice work is not limited to medical decisions, but is related to the wide variety of decisions patients and family members face at the end of life.

Hospice workers sometimes find themselves trying to encourage patient autonomy when patients resist it. Often from a distance it appears that these patients are simply deferring to medical authority since they often state that they will do whatever the doctor recommends. Sometimes these patients are really resisting making choices for social reasons, as in the example of Dottie avoiding the decision of whether to switch from a catheter to adult diapers because of the complex social and financial burdens the change would impose on her son. Dottie's nurse Ellen encourages her to make this choice, but Dottie ultimately is not ready to do so. In other instances patients or families

resist making choices because they are not psychologically ready to accept or prepare for death.

Hospice workers understand these psychological limitations on decision-making about dying. By fostering patient autonomy they are not only facilitating patient choice, but accepting the idea that some patient choose not to decide. The act of not making a decision about something like funeral arrangements is itself a choice that conveys that the patient or family is not ready to tackle this issue. Hospice workers often walk a fine line, encouraging patients and family members to make choices that they may not be ready to make. Many hospice workers believe that presenting patients and family members with education about their choices earlier rather than later alleviates problems down the road, but they recognize that it is always up to the patient and family members whether to act upon their recommendations. One social worker, Megan, describes how she encourages patients and family members to make final arrangements, but accepts that many are not psychologically ready to perform this task.

You know, I always in the initial meeting, I gave—like I said, everyone is different, so I kind of read them—I try to meet them where they're at. And, I let them know that I'm here to help if they need it but I don't push anything on them because if they're not ready to talk about it, if they don't want to set it up, that's okay. It's obviously going to be a little bit more stressful when that time comes, but that's just—if they're just not capable of doing the—being prepared, doing that work, I'm not going to force them on it... Basically I find that—as long as they know that I'm here to help. And, I'll tell them, a lot of times I'll just say that. I said, I just need to let you know that I'm here to help you with those arrangements, but you don't feel like you have to do it. So that—because the worst thing that can happen is that nobody brings it up and then they're stressed. That's an additional stressor on them. You know, like I need to pick a mortuary. I don't even know, you know, if I want to be cremated or a full burial. If these things are going on in their head and they didn't know that I'm here to help them do that, then that could make it a lot worse. And, you know, unfortunately sometimes me mentioning that I do that, I have a lot of

people cry. I mean, I get a lot of people to cry, you know, so I just--Just to let them know that it's there, because you know what, the worst case scenario, they don't do any planning, the person passes, they just have to make some last minute decisions.

Here Megan demonstrates how she respects a patient and family's choice, whether or not they are ready to tackle the question of final arrangements.

In other cases patients and family members might have a passive approach to medical care that leads them to avoid some decisions. Hospice workers often need to encourage patients to ask for help when they need it or to convince patients that patients are in charge of hospice worker visits, including when they are scheduled and how long they last. Often patients are used to adopting a more passive role from prior experiences with the health care system, and are initially confused by the flexibility of hospice. Eva, a hospice nurse, describes how one of her patients always expects the nursing visit to last for exactly 60 minutes.

So for them to be a person and not to be a number is different. They'll be like, I've never had a nurse sit with me for an hour. And sometimes some people are like, well okay I know you have to leave, and they are watching the clock. I have to tell them, I have one particular patient, he loves our visits, but he'll watch the clock, and when it gets to be an hour he'll say, okay I'm going to let you go, because I know you have other patients to see. And I'll say to him, I'm not watching my clock, I'm not looking at my watch, and you shouldn't feel like I have to go anywhere, and I hope I don't make you feel that way. And he'll say, no, no, but I know that you have other patients to see and I don't want, and it's like, no, no, no, I'm here to see you. And if I have to be here for two hours then that is fine with me. I have room in my schedule to do that. But if you want it to be less I can be here less, and you can take the cues from the patient and the family.

The shift from the passive mentality associated with hospital based medical care to the patient-centered focus of hospice is often problematic for patients. Although

patients with confidence and medical expertise like Henri (the former physician) made a majority of care decisions, many patients relied on hospice workers to guide them in many health related decisions. Hospice institutional policies and practices enable this freedom on the part of both their patients and staff encouraging a flexibility that responds to patients' preferences and needs.

Respecting patient autonomy does not mean that hospice workers condone all patient decisions. Many hospice workers strongly believe that certain decisions are beneficial to patients and families, including administrative decisions such as planning final arrangements ahead of time and psychological decisions, such as accepting that death is near (Zimmermann 2012). When patient preferences and hospice worker expertise clash hospice workers often try to educate the patient about the issue in order to have them reconsider.

Sometimes these clashes appear to be about a smaller issue, such as medication, but are really symbolic of a larger issue, such as whether to acknowledge that death is near. In the following example I show how Steve wants to return a medication he does not need anymore to hospice, and his social worker convinces him that he should keep it in the house since he may need it again in the future, a subtle reminder that his health will eventually decline more. During a visit with Steve his social worker, Kathy, asks Steve if he is experiencing any pain (a standard question all hospice workers ask on all visits). Steve replies that he has been doing better and has not had any pain recently, in fact he mentions that he has some Lidoderm patches (pain medication) leftover from a bad pain

spell that occurred earlier and he asks Kathy if he can return them to hospice⁴⁷. Kathy suggests, “Maybe you should hold onto them for a few weeks to make sure you do not need them. It would be better to have them around in case you need them.” Steve acquiesces, apparently seeing her logic. He seems to be reminded of the progression of his illness by Kathy’s comment, the next thing he does is mention that during his last visit with his nurse she explained to him the changes he would experience as his disease progressed. Steve, who is a former English teacher and has a knack for expressing himself says this knowledge is, “scary, one does not want to truncate one’s being.” In this example we see how medications are symbolic, and represent decline and possibly death. It is also fascinating that a decision about medications, such as whether to keep Lidoderm patches in your medicine cabinet, is a decision about whether to acknowledge and prepare for dying. Steve expresses a preference, which Kathy thinks is unwise, and after she coaxes him he agrees to keep the medication. This example illustrates some of the complexity of the application of the principle of patient autonomy; ultimately it was Steve’s decision, but he was reacting to Kathy’s advice.

I find that hospice workers delicately balance the need to respect patient preferences with their own desire to make the experience of dying easier for patients. Health care services research on the philosophy and provision of hospice care finds that hospice sanctions a “patient centered” approach that places patient (and/or family member) preferences at the crux of each decision (Carlson, Barry, Schlesinger, McCorkle, Morrison, Cherlin, Herrin, Thompson, Twaddle, and Bradley 2011).

⁴⁷ Pacific Hospice workers are responsible for safely disposing of patients’ unused medications.

However, the hospice philosophy sometimes clashes with patient preferences, most notably in the case of patients who do not accept that they are dying (McNamara, Waddell, and Colvin 1995; Zimmermann 2004). Ultimately in the stories that I heard recounted a patients preferences appeared to be the weightier factor.

Sometimes with patients that are not ready to acknowledge they are dying, hospice workers may try to gently reframe what one spiritual counselor referred to as the patients' "future hopes". Spiritual counselors told me about several patients who posed a special challenge because they truly believed God would send them a miracle and heal them. Here a spiritual counselor, Barbara, explains how she tries to "reframe the hope" of a man who avidly watches "The 700 Club" on television (a religious program in which people routinely are miraculously healed) and believes his wife will be healed of her terminal illness.

Trying to slowly go in to open the door and not take away that the miracle is going to happen but that the miracle might look different than the one he really wants which is complete and absolute and miraculous healing. But you know, you see these cases where two family members haven't spoken in 20 years, you know, somehow in this situation they reunite. To me, you know, that could be the miracle or you know, convincing—not convincing, I don't want to use that word, but helping him maybe reframe a little bit and recognize that yes, his faith in God is a strength and yes, I believe with him that God does care, that God does love him and that God is and will work in this situation and that we trust, that yeah God is working. But that what God will do might not be his deepest hope. So, I guess I try to, you know, say God we look—these are our earnest desires of our hearts to you, we trust you with them and--

Part of the skill of hospice workers is knowing when to and how to try to guide patients to make a choice, in this case, the choice to acknowledge dying. At other times hospice workers back off and acknowledge that they can not force a patient to do what

they think is best, and that indeed, some patients deaths will be more difficult as a result. Barbara has to resist the temptation to use the word “convince” when describing the patient above, but she like other hospice workers repeatedly told me they tried to keep their personal values out of their work.

In some instances hospice patients experience deaths that hospice workers view as involving needless suffering, but hospice workers acknowledge that this outcome was the patient’s choice. One hospice nurse, Stacey, gave me an example of a hospice patient she worked with who did not want a Do-Not-Resuscitate order, and ended up dying in a hospital emergency room after receiving what Stacey saw as a brutal and ineffective CPR. Patients who refuse to accept that they are dying are a challenge for hospice workers, yet by putting patient preferences first even these cases can be construed as successes of a sort. Stacey tells me, “My goals aren’t always their goals and I have to be careful of that, that I’m really there to support their goals.” Other hospice workers tell me that these patients died “the way they wanted to.” Hospice workers also reconciled themselves to the idea that they can not help every patient⁴⁸ and that even with hospice care some patients will experience much pain and suffering.

As these example show hospice work encourages patient autonomy in various ways. The very structure of hospice work, the home setting, and interdisciplinary team provide a foundation for demedicalizing the end of life experience and accentuating

⁴⁸ In fact one nurse, Tracey, told me her hospice team manager had a story he frequently told the staff to symbolize their role: There is a little boy walking on the beach and there are lots of starfish lying in the sand. He starts picking up the starfish and throwing them back into the ocean. He goes down the beach picking up starfish and throwing them into the surf. A man comes up to him and says, "you know you'll never be able to save them all." The little boy picks up another starfish and throws it back into the ocean and says, "Well I just saved that one."

social concerns. The demedicalizing traits of hospice care accentuate the importance of the illness experience over physiological or biological changes, empowering patients by showing them that their social context is as or more important than medical or technical knowledge. By facilitating the view that dying is natural and normal hospice workers teach patients and families what to expect during the dying process and what choices they can make. The emphasis on holistic care also empowers patients and encourages hospice workers to respect their decisions. Many hospice services are optional, such as the use of volunteers, home health aides, spiritual counselors and grief counselors, and other preparations for dying that hospice workers encourage are ultimately personal decisions. Patients and family members often appreciate the education and preparation that hospice provides and take advantage of it to plan ahead and make decisions ahead of time. However, in other instances patients resist making choices and sometimes resist the idea that they are dying. Hospice workers are not impartial observers, they try to encourage patients and families to do what they think will reduce suffering and ease a difficult experience, but if patients resist their recommendations they generally accept that a patient's preferences trumps their professional expertise.

CONCLUSION: DEMEDICALIZATION + HOLISTIC CARE = PATIENT AUTONOMY

The evidence presented above suggests that hospice work enhances patient autonomy to an extent unusual in other medical encounters. Hospice's institutional structure fosters autonomy by providing an interdisciplinary approach and a demedicalizing influence, and by emphasizing the holistic nature of dying which

prioritizes the patient's illness experience and preferences. Hospice workers also facilitate patient choice by guiding patients through difficult decisions that are not just medical in nature, but also social, psychological, spiritual, and administrative. This overview does not suggest that hospice workers are unbiased bystanders, instead they use their expertise to try to guide patients towards what they consider the best decision given what they know of the patient's illness, preferences, family, finances, and spirituality. In this sense hospice workers act as consultants offering patients information, and stepping in to make decisions when patients indicate that they do not want to make a choice.

This chapter suggests that hospice institutionalizes a form of caring that encourages patient autonomy. The type of care provided by hospice is distinct from some other forms of medical care for two reasons: it is a demedicalizing influence and it emphasizes holistic care. Although I do not contend that hospice fully demedicalizes dying (or attempts to), it works to make dying less a medical event and more of a psychosocial event. Hospice workers do this by discouraging medical care they see as intrusive or ineffective and by stressing social not medical reasons for many interventions. I argue that the medical aspect of hospice work is subsidiary to its larger mission of reducing suffering and improving the end of life experience for patients and families.

Hospice workers encourage a view of dying that is holistic and not strictly medical. While some research has contended that hospice has medicalized suffering (Fox 2010), I suggest that suffering is considered a holistic phenomenon. Hospice workers address a number of non-medical concerns with hospice patients. They focus on helping

patients mend relationships, ease spiritual suffering, say good-byes to family and friends, and even perform mortuary and funeral planning. In a certain light this work could be reconceptualized as “medical” work, since technically it is often performed by hospice workers and paid for with Medicare dollars. A sociologist bent on detecting medicalization could argue that the very holistic nature of hospice is evidence for medicalization since it is performed under the umbrella of hospice care, a medical institution, funded by medical insurance money. However, I suggest that in order to discuss medicalization it is necessary to define *who* is defining or treating an issue as medical, and in this case it is clear that patients, families, and hospice workers all see these decisions as social in nature. Medical care and issues are necessarily an important concern for quality of life, but in this study they were by no means a patient's only concern or even the biggest concern⁴⁹.

In this chapter I contend that the hybrid nature of the hospice institution combining some elements of traditional medicine with a home setting and ethos contributes to enhancing patient autonomy. Similarly the demedicalizing influence of the institution and the goals of holistic care are congruent with the principle of patient autonomy. Demedicalization and holistic care shift the power balance of the medical care encounter away from professionals and toward the patient or family. While doctors may be the authorities with the most expertise on how to *cure* disease, when it comes to how

⁴⁹ An important caveat to this point is that my study included only patients who were relatively stable, as defined by hospice staff. Patients in severe pain or with uncontrolled symptoms were not eligible for this study. Several hospice workers suggested that until a patient's pain is under control it is often their dominant concern. Once pain is under control, or for the patients who do not experience serious pain problems, other non-medical concerns come to the forefront.

to improve quality of life and improve holistic *care* only patients and family members can judge what constitutes an improvement. Hospice workers accept that patients' preferences may diverge from what they think will lead to the best outcome, as Stacey indicated in the case of the patient who died while receiving CPR at a hospital. Hospice workers may try to guide patients to a new mindset, as with Barbara trying to "reframe" her patient's hopes about God granting a miraculous recovery from her illness, but they accept that the patient must lead in terms of both big decisions and smaller ones such as what words to use when discussing dying.

This analysis of hospice work does not suggest that all patients desire autonomy. Indeed an important part of respecting patient autonomy is recognizing when patients resist decision-making. Nor does this analysis of hospice work indicate that hospice only enhances patient autonomy. There are important caveats to the argument that hospice accentuates patient autonomy. First, as demonstrated in Chapter 4 patients resist making choices for myriad social reasons some of which may be more pronounced in the home setting. Second, hospice like any institution can be a constraint on choice. Third, in many cases the term "patient autonomy" is misleading. Although the sample of patients in this study were all still able to communicate and make their own decisions, many hospice patients are already incapacitated or have such severe dementia that they can not express their own preferences. In these cases family members decide what they think the patient would want or what they think is best for them (Brudney 2009; Haley et al. 2002). In a subset of these cases patients are alone and presumably hospice workers or other health care workers (e.g. nursing home staff) may be called upon to make decisions for a

patient. Yet alert hospice patients in this study experience a freedom of choice within home hospice care that is remarkable.

Hospice as an institution precludes some choices. For example, like other medical institutions, hospice selects which medications a patient may be prescribed. Hospice cannot cater to patient's every preference. Sometimes hospice workers are unable to visit hospice patients at the most convenient times. In other cases, some people seemed shocked that hospice does not provide round the clock hands on care or care on weekends or holidays. Rhonda, Charlie's live in caregiver, was particularly outspoken about her disappointment that hospice would not take on this responsibility, despite the fact that on-call hospice staff had on several occasions come to see Charlie and his wife on weekends or at night when there was an emergency. Perhaps the biggest way in which hospice restricts patient choice is through the very choice to enroll in hospice, which precludes curative medical care. In the next chapter I put the institutional world of hospice into perspective by focusing on the other institutions that influence hospice care and patient autonomy: Medicare and the field of Medicine.

I argue that hospice practices and structures although in some respects unique, are replicable within other health care institutions allowing us to further patient autonomy through following the hospice model. The emphasis on the entire illness experience and on caring instead of curing, while hallmarks of hospice care are applicable to the growing segment of health care which is concerned with caring. Other medical institutions could replicate some of the beneficial aspects of hospice philosophy and practice. A growing segment of the health care field is concerned not with strictly curing disease, but with providing care, including long term care for patients with disabilities or chronic illnesses.

Certain features of hospice's institutional structure and workers interactions with patients and families could be translated into practices that could change the wider field of medicine and health care.

This chapter is currently being prepared for submission to journals for publication. The dissertation author was the primary investigator and author of this material.

CHAPTER 6. CONCLUSION: THE ROLE OF EXTERNAL INSTITUTIONS

Until now sociological research has focused on how large medical institutions such as the medical profession and Medicare further medicalization and constrain patient autonomy. This focus ignores the ways in which these external forces can include demedicalizing influences and actually promote patient autonomy. In the first part of this chapter I review two powerful external institutions, Medicare and the medical profession, and how they impact hospice care. In the second part of this chapter I provide an overview of the study findings and implications for the field of hospice care, the broader field of health care, and for social attitudes toward dying itself.

Both Medicare and the professional domain of medicine have complex relationships with hospice care and end of life care more broadly. These institutional players play a contradictory role, both expanding and reducing patient choice. For example Medicare presents patients with a new option, hospice, and then imposes severe limitations on those patients choosing that option. The field of medicine itself also exerts a powerful influence on who has access to hospice care and what form hospice care may take. Physicians as gatekeepers enable and limit patient choices, and the medical profession's efforts to establish a new field of Palliative Care also complicates the choices patients face. This study shows a tenuous balance between medicalizing influences and the demedicalizing influence of hospice care. That balance is unstable and

the future of hospice care is uncertain as changes such as the rise of the field of Palliative Care may be a new medicalizing influence.

MEDICARE: FORCING A CHOICE

Medicare has two powerful effects on hospice care and the experience of dying in the United States. First, it acts as a demedicalizing influence by institutionalizing, funding, sanctioning, and regulating a form of care, hospice, which responds to dying holistically. Second, Medicare forces patients to choose between mainstream medicine's cure-oriented treatments, and hospice with its demedicalizing tendencies. As discussed in Chapters 2 and 3 this choice is often perceived not as a medical choice between cure and care, but also as a social choice between living and dying.

Medicare has been the greatest force in expanding the size and scope of the hospice movement in the United States, since it began funding hospice care began in 1982 (United States Congress 1982). Without Medicare funding it is likely that hospice care in the United States would have remained a small, exclusive, and poorly funded niche (Siebold 1992). Yet Medicare funding is a double-edged sword; it opened up the option of hospice care to a growing number of Americans, but it imposed severe restrictions on hospice eligibility. These eligibility restrictions designed to control costs, function to restrain patient choice by making hospice an either or choice: choose hospice or choose curative care.

Medicare's False Dichotomy: Cure and Care

Due to concerns about controlling costs Medicare, the primary payer of all hospice care in the United States, forces patients to choose between curative care and hospice care. In 2011 84.0% of all hospice patients were paid for through Medicare (National Hospice and Palliative Care Organization 2012). Medicare's regulations state that hospice patients cannot simultaneously receive hospice care and curative care at the same time. Medicare stresses, "When you *choose* hospice care, you've *decided* that you no longer want care to cure your terminal illness and/or your doctor has determined that efforts to cure your illness aren't working (Medicare Hospice Benefit 2011, 7, my emphasis). Medicare, created this either or choice between hospice and curative care in order to save money.

This choice promotes a demedicalized view of hospice and reinforces the idea that choosing hospice is a social decision. The idea that hospice is for those who "no longer want to cure" their illness or for those whose doctors decide they will not be cured, fosters the stigma that hospice as an institution works hard to avoid. It suggests that hospice is for those who have "given up" on medicine or those whose doctors have given up on them. Further it suggests that medicine is about curing, hospice is about caring, and that the two cannot be combined. The impact of these Medicare regulations goes well beyond the effect on patient choice. By setting up an opposition between hospice and curative care, Medicare fosters the stigma that hospice is for "dying" and curative care is for "living". Medicare is influencing our ideological categories of living and dying.

The official requirement of a patient prognosis of six months or less also contributes to a false dichotomy between living and dying. As Colleen recounts in her

story about when her mother was accepted to hospice care, in the span of one day she went from thinking of her mother as living to thinking of her as dying. Reflecting on her reaction, Colleen says, “Well six months to live, right? The fact that they accepted her as a Hospice patient made the whole idea of death more real than either of us were prepared for.” Although no doctor ever told her mother an official prognosis, beginning hospice care was a prognosis itself, one that defined her mother as dying. In this sense Medicare is not only limiting patient choice, it is defining “dying”. This definition is somewhat arbitrary. If Medicare eligibility for hospice were based on a prognosis of nine months or a year, many patients would still think of themselves as dying. Alternatively Medicare could eradicate the prognosis requirement, opening hospice to all patients with serious chronic or terminal illnesses and ending the forced choice between cure and hospice care⁵⁰.

The issue of prognosis seemed to be misunderstood or glossed over for many patients. Even Henri, the physician who was a former head of a hospital emergency department and who had ample knowledge of hospice care said that at the time he started hospice care he believed that Medicare had revoked the six months prognosis requirement.

Henri: And you know the other thing that has changed with hospice, although Ellen [his nurse] says it is still in the regulations. It used to be that to qualify for hospice you had to have a less than six months prognosis to be enrolled. And obviously physicians were in a difficult position to write that. Unless somebody is really declining and you could

⁵⁰ A pilot study of allowing patients full access to both curative and hospice care by Aetna found that usage of hospice care increased, use of acute care decreased, and costs decreased. Krakauer, R., C. M. Spettell, L. Reisman, and M. J. Wade. 2009. "Opportunities to improve the quality of care for advanced illness." *Health Affairs* 28:1357-1359.

see they're not going to last long. And patients would have, also, a difficulty accepting it. And although apparently, I mean I thought that they had given up on that completely, it is still part of the Medicare regulations, but they don't mention it anymore.

Interviewer: Oh really? Who does not mention it?

Henri: Hospice and what not. I don't think there is the same pressure on the doctors to give a six month prognosis.

Interviewer: So you think that doctors don't necessarily tell patients that before they start hospice?

Henri: Right. No longer. Certainly nobody mentioned it...

As I discuss above the association between hospice and dying is both a blessing and curse. As long as patients think of mainstream medicine in terms of “cure” and hospice in terms of not curing (which is tantamount to dying) many patients will avoid hospice care. Yet much of the work hospice workers do to help prepare patients for dying depends upon the acknowledgment and acceptance that they are indeed dying. Taking away the requirement for a terminal prognosis, or changing the name from “hospice” to “palliative” care may dilute the potency of the work hospice care is doing.

Decertification: Graduation or Abandonment?

Medicare regulations concerning recertification of hospice patients also restrict patient choice by strictly limiting how long patients can use hospice care and requiring periodic recertification. The Medicare hospice benefit was intended to be used for six months or less, hence the need for patients to have a prognosis of six months or less. Medicare regulations require that hospice staff “re-certify” patients after their first 90

days with hospice, then again after another 90 days, and then afterwards in 60 day increments. Other researchers have written about the significant number of patients who are *decertified* from hospice care, either because their condition improves or they do not decline enough, in these cases their hospice eligibility is revoked and they must cease hospice care (Fox 2010). Ending hospice care can be a serious hardship for patients who rely upon hospice for medical care, home health services, and even companionship. For some of these patients the abrupt end of hospice services is experienced as abandonment, and can harm their health and psychosocial well being.

For other patients decertification is not experienced as abandonment, but as a sign of success. These patients are happy to end hospice care when their health improves or stabilizes. Hospice workers refer to this process as “graduating” from hospice, putting a positive spin on the loss of one form of medical care. A hospice social worker, Kathy, told me the story of her uncle who was previously a Pacific Hospice patient, but his condition improved, he was decertified, and is now living on his own, and has become a hospice volunteer himself, going to patient’s homes to give them hair cuts. One of the patients enrolled in my study, Carolyn, was in her second round of care through Pacific Hospice. She received hospice care about 6 years before this study, but she improved, and was pleased to get off hospice care. In the case of decertification patients are not given a choice, Medicare will no longer fund their care. Unless a hospice is willing to continue to provide care to the patient *pro bono*⁵¹, they must cease hospice care.

⁵¹ NHPCO estimates show that in 2010 1.5% of hospice patients were classified as “Uncompensated or Charity Care”, suggesting that hospice’s may begin or continue services for unfunded patients in some cases. National Hospice and Palliative Care Organization. 2011. "NHPCO Facts and Figures: Hospice Care in America."

While Medicare seems to restrict hospice patients' usage of its service by its strict eligibility and recertification requirements, there is some evidence in this study that certain patients and hospice workers find a way to turn these restrictions to their advantage. Patients have the right to discontinue hospice care and resume curative care at any time, and in this study a few patients took advantage of this maneuverability going back and forth between hospice and mainstream medical care. Gene, who was always ambivalent about ceasing curative care on several occasions was admitted to hospitals for curative care and then restarted hospice care. In other cases patients would cease hospice care for the sake of a single hospitalization and then be re-admitted to hospice. I did not collect data on the frequency or process of these hospice re-admissions, it is not clear whether patients were instructed in how to do this by hospice workers, community physicians, or family members. However, there does seem to be a group of patients who make "hospice patient" a more fluid status. Research on this topic finds different reasons for live discharges from hospice, and that a substantial minority of patients were re-admitted within six months (Kutner, Meyer, Beaty, Kassner, Nowels, and Beehler 2004). In total, 19% of discharges were attributed to "patient/family decision" or "pursuit of more aggressive treatment" (Kutner et al. 2004, 1339). As their evidence suggests even in the absence of formal decertification many patients or family members make personal decisions to end hospice care prior to death.

While Medicare does restrict patient autonomy by severely limiting choices, it is worth remembering that Medicare coverage of hospice has also expanded the options for patients receiving end of life medical care. Historically it has opened up an important alternative to mainstream medical care, and usage of hospice care continues to climb in

the United States each year. However, Medicare does force patients to make an unpalatable choice between cure-oriented and care-oriented options. Medicare also revokes care if patients do not meet its prognostic criteria. However, patients retain the ability to decide if they want to pursue hospice care in the first place, and can opt out of it at any time, and in some cases opt back into it. Medicare provides an example of how the same institution can expand and restrict patient choices, and because of its national importance it can simultaneously change the social meaning of these choices.

THE MEDICAL PROFESSION

There are two fundamental ways in which the field of medicine influences the role of patient autonomy with regards to hospice care. The first is through the direct mechanism of physicians acting as gatekeepers. The second is through the professional dynamics surrounding the burgeoning field of Palliative Care (sometimes known as Palliative Medicine), as distinct from the more established field of hospice care. In the case of physician gatekeepers, evidence suggests physicians largely restrict patient autonomy by restricting access to and information about hospice care and either not making referrals or making them too late in the dying process. In the case of the changing structure of the field of hospice and Palliative Care there is both evidence for and against improved patient autonomy.

Physicians as Gatekeepers

For some patients hospice is a choice that a physician offers to them, other patients never experienced choice they were “sent”, “transferred”, or “discharged” to hospice never understanding that it was optional. Even among those whom were presented with hospice care as a choice, I show in Chapter 3 that the perception of how physicians referred patients to hospice strongly influenced whether patients welcomed or feared hospice care. Physicians sometimes educate and encourage patients to transition to hospice, other physicians “give up on patients” or “abandon” them to hospice actually deterring some patients from accepting hospice care. The process of referral can contribute to a negative form of demedicalization. Hospice is framed as something separate and apart from mainstream medicine, which treats disease. Hospice treats dying, both its biological and psychosocial consequences. In particular when referrals reflect an attitude that medicine can not do anything to help the patient, the referral is perceived as transferring care into a new domain, that of dying. Physicians play a powerful role in shaping decisions about hospice care, and unfortunately many physicians negatively skew patient attitudes toward hospice.

The Field of Palliative Care

However, it is not just physicians’ direct interactions with patients that influence patient options and choices. The structure of the field of medicine and historical changes in the role of hospice care and the growing field of Palliative Care also exert a strong influence. The development of hospice care and the now expanding field of palliative

care are institutional mechanisms for providing more choices for patients at the end of life. From its inception hospice was conceptualized as an option, a choice, and an alternative to mainstream medicine for individuals at the end of life. The growing field of palliative care represents yet another new choice for patients. Still little understood by the general public, the field of palliative care is gaining recognition within medicine and theoretically furthers patient autonomy by allowing patients to pursue both a curative and palliative approach simultaneously.

The National Hospice and Palliative Care Organization (NHPCO) defines Palliative Care as, “to make comfortable by treating a person’s symptoms from an illness... The goals of palliative care are to improve the quality of a seriously ill person’s life and to support that person and their family during and after treatment” (National Hospice and Palliative Care Organization 2013). In a description meant to dispel confusion about distinguishing the terms “hospice” and “palliative” care, the NHPCO points out that Hospice is designed for patients with a prognosis of months, while palliative care can apply to patients at any stage of an illness⁵². The official distinction

⁵² Full text of NHPCO description: “You may have heard of a new medical term – palliative care (pronounced PAH-LEE-UH-TIVE). For the last thirty years, palliative care has been provided by hospice programs for dying Americans. Currently these programs serve more than 1.2 million patients and their families each year. Now this very same approach to care is being used by other healthcare providers, including teams in hospitals, nursing facilities and home health agencies in combination with other medical treatments to help people who are seriously ill. To palliate means to make comfortable by treating a person’s symptoms from an illness. Hospice and palliative care both focus on helping a person be comfortable by addressing issues causing physical or emotional pain, or suffering. Hospice and other palliative care providers have teams of people working together to provide care. The goals of palliative care are to improve the quality of a seriously ill person’s life and to support that person and their family during and after treatment. Hospice focuses on relieving symptoms and supporting patients with a life expectancy of months not years, and their families. However, palliative care may be

between the use of the word hospice and palliative in the United States is essentially that hospice addresses care of the dying and Palliative Care can be ostensibly used for any patient at any stage of illness to reduce their pain and discomfort (Mitka 2012).

Although historically the terms hospice and palliative care have been intertwined in practice and theory, today there is an effort underway to make an institutional space for palliative care (or sometimes palliative medicine) as distinct from hospice care, for example in hospital palliative care departments. Palliative care is not limited to occurring within hospice care organizations. For example Palliative Care departments⁵³ within hospitals are growing dramatically, between 2000 and 2003 the percentage of hospitals with Palliative Care departments grew from 15% to 25% (Morrison, Maroney-Galin, Kralovec, and Meier 2005). While historically palliative care was under the umbrella of hospice care and included many holistic and non-medical measures (such as spiritual counseling), the growth of a medical field of palliative care raises questions about the medicalization of what was intended to be a demedicalizing form of care.

If Palliative Care departments exist in 25% of hospitals, theoretically more patients should be given the option to receive both curative care and palliative care

given at any time during a person's illness, from diagnosis on. Most hospices have a set of defined services, team members and rules and regulations. Some hospices provide palliative care as a separate program or service, which can be very confusing." —. 2013. "Palliative care: How can palliative care help?".

⁵³ Brigham and Women's Hospital in Boston includes this description on its webpage for its Adult Palliative Care program: "Palliative care can be helpful through all stages of illness. Early on, it can help make medical treatments more tolerable; at later stages, it can reduce suffering, help you carry on with daily life, assist you in planning for future medical care, and provide support for living with a life-threatening illness. Palliative care focuses on the whole person: body, mind, and spirit. Our team of professionals aims to provide comfort, preserve your dignity, and help you achieve open communication with your family and caregivers." Brigham and Women's Hospital. 2013. "Adult Palliative Care: Our Services."

concurrently. This option might represent a happy medium to patients and doctors who do not want to be forced to choose whether someone is dying or living. Yet physicians act as gatekeepers to hospital based palliative care, just as they do with hospice care. Current evidence shows that physicians refer patients to hospital palliative care departments at low rates, and often when curative treatments have ended (Kelley and Meier 2010). The fact that the term palliative care is used in reference to both hospice and non-hospice (hospital) care and uncertainty about what “palliative” means leads to some confusion. Evidence from my research suggests a lingering confusion among hospice patients about what palliative care means, and whether it is different than hospice care.

While “hospice” is feared and stigmatized, palliative care is less familiar concept. The term “palliative care” may be more palatable to patients than the term “hospice” because it represents a set of tangible actions that will reduce discomfort, while “hospice” represents an existential threat. In response to my question about how he started hospice care, Gene explains what he remembers:

Well I remember the time when the doctor told me, he said I'm going to ask hospice to come. And I objected to that, very much so, because my vision of hospice was - well you're dying and you'll be dead soon and hospice is there just to see that you get, that you face death as calm as possible. And I objected to that because that was my sole knowledge of hospice. And then he said no it's palliative, and then I said, well let's explain that a little more. And he did, and then I saw that, I've known all along that when my cancer spread and went into my spine and into my bone marrow, I knew that it had a grip on me. I knew what the final outcome would be. So when I learned more about hospice in a palliative way it became more acceptable to me.

Gene nicely demonstrates the mixture of emotions that can accompany starting hospice care. This quote shows the stigma about what hospice means and the more positive response to the term palliative care. Gene thought hospice was a way to get him to face death calmly, but when his doctor explained its purpose was to palliate or make him more comfortable he agreed to try it. Still in this and other conversations about palliative care it was not always clear if patients and others thought palliative care was a component part of hospice care, a separate type of care entirely, or a revolution within hospice care. While a motivated patient and family could easily learn exactly what palliative care and hospice care mean by asking hospice staff or searching resources online, many patients and family members do not have the time, energy, or motivation to explore these issues when they first begin hospice care.

Further complicating decisions about palliative care is the fact that professional entities and hospice workers themselves sometimes lump hospice and palliative care together and commingle terms like “Palliative Care” and “Palliative Medicine”. For example, professional efforts to gain recognition of the role of hospice and palliative care led the American Board of Medical Specialties to create a new specialty for “Hospice and Palliative Medicine” in 2006 (Quest, Marco, and Derse 2009; von Gunten and Lupu 2004). While some of these issues may be semantic, there is a very real question at stake about whether hospice and palliative care are primarily seen as “medicine” and part of the larger medical infrastructure, or whether they are fundamentally different.

The recognition of the subspecialty seems to offer proof that hospice and palliative care are becoming medicalized and brought further into the fold of mainstream medicine. Field discusses the concern that the broad holistic goals of palliative care might

be medicalized, “the medical penchant to (over)use technical procedures is viewed with suspicion and there is a fear that the ‘holistic care’ of hospice patients may gradually become subverted” (1994, 61). In this sense the medicalization of palliative care might also compromise the hospice movements efforts to demedicalize dying.

The expansion of palliative care also muddies patient choice, by creating more confusion about what hospice and palliative care mean. Charlie, the 86 year old man with Debility Unspecified and heart disease living with his wife who has severe dementia, repeatedly discussed his frustrations about what exactly hospice meant in terms of the care that he would receive.

Interviewer: And did you know very much about Hospice before that?

Charlie: No, I didn't. I knew what Hospice was as far as, you know, taking care of you towards the end, but I was not aware of the palliative arm.

Interviewer: And when you say the palliative arm, like what things are you thinking of that they did that you weren't aware of before?

Charlie: Well the palliative -- I wasn't aware that they really were not active in getting you well. They were active in maintaining. I wasn't really clear on that.

Charlie’s dialogue seems to conflate the idea of palliative care with non-curative care. Meanwhile the field of palliative care would like to encourage the idea that palliative care can accompany curative care, it is not a zero sum game. However, Charlie and a few other participants in this research also indicated that they thought palliative care was different from hospice care, in that it was not intended for dying patients. Charlie believed that Pacific Hospice has a hospice arm and a palliative arm and that hospice caters to both people who are dying and those that are simply experiencing a

serious illness. Here Charlie explains how Pacific Hospice caters to dying patients and another group, those with chronic illnesses like himself: “And the problem with that, primarily they [hospice] were founded on the premise of just taking care of someone who was dying and making it easier on the family. That was their calling. And then they expanded a little bit to take care of people who were in fairly good health, you know, but could benefit from the kind of care they were giving to the end of life people.” Another participant, a hospice volunteer for eleven years and former pediatric nurse, Beverly, also reveals that she believes hospice has two groups of patients: dying patients and palliative care patients: “And now though it’s probably because with the palliative care the staying with the patient tends to be longer, because with palliative care they’re not on hospice because they’re expected to die within six months.” The distinction between the terms and goals of hospice and palliative care seemed to confuse a group of patients in this study.

Often the hospice staff’s own use of the word “palliative” care was confusing to patients. When Gene’s health was rapidly declining and he was very weak, I observed a visit during which his nurse Stacey and he discussed doing what Stacey dubbed a “palliative transfusion”. Gene was receiving blood transfusions before his hospice care began and at that time he understood them to help treat his disease and he viewed them as helpful in giving him energy and making him feel better. He requested a transfusion during Stacey’s visit and there was a lengthy discussion about where and how to get a transfusion and whether it’s positive effects would outweigh the cost in terms of energy and stress of him going to get the transfusion which would probably require an inpatient stay at the hospice facility. Gene at times seemed confused about what a “palliative

transfusion” meant since the actual treatment would be the same as it was before he started hospice, but eventually he assures the nurse he understands the transfusion will not “reverse the disease.”

Medical professionals outside of hospice may also contribute to the confusion about what constitutes palliative care and what constitutes curative care. Doctors do not always label a treatment as curative or palliative. More often doctors simply tell a patient they need to have a transfusion, or radiation, or surgery. It is not always explicitly stated whether the purpose is palliative (reducing discomfort), curative (curing the underlying disease), or both. One of the volunteers participating in this study, Lindsay, was a radiation therapist by profession and she talked at length about the hospice and non-hospice patients she saw coming in for radiation on a daily basis. Lindsay describes her dismay at hospice patients coming in for aggressive radiation treatments, and even mentions certain radiologists deciding to switch patients from palliative to curative regimens of radiation when they think it is justified.

Lindsay: And it's disheartening when you see someone who goes on Hospice care and so you know that they've got that six-month prognosis and yet they're getting extremely aggressive treatment extremely late, life-preserving.

Interviewer: And are they doing that because they classify it as palliative or are they...

Lindsay: Well like you'll see Hospice patients but not palliative. It will be curative treatment... And it's even among like the physicians like some... Like I'll see physicians who will say, “well no, I'm not going to treat this palliatively. I think that this is not something that should be validated. Like I think this should -- we should go with a curative intent...”

I argue that confusion in the use of the terms hospice, palliative care, and palliative medicine, is not just a semantic concern, it has a profound effect on patients. Notably, Charlie regretted his decision to begin hospice care because at the time he did not realize that palliative care (in the hospice context) meant he could no longer receive curative treatments. This lack of understanding about the criteria and consequences of being a hospice patient indicate these patients did not truly have what we would consider “informed consent”. Even patients who clearly understood hospice did not provide curative treatments sometimes did not realize that hospice patients must have a prognosis of six months or less to live, as described in the above section in the example of Henri the physician.

One of the most basic philosophical tenets of hospice care is that patients should accept and plan for their own death. If patients are unaware of their prognosis how can they realistically prepare for dying? The expansion of palliative care as a field that is separate from hospice care threatens to dilute this very powerful component of hospice and jeopardize the focus on preparing for death. Citing Biswas (1993), Field comments upon this issue (1994):

Biswas argues that this ‘is a shift in emphasis which alters the original concept of improving care for dying people’ and that it may lead to the disappearance of the explicit recognition of death by pushing attention ‘downstream’ to such an extent that terminal care becomes marginalized within palliative care. ‘Palliative care shifts the focus of attention away from death and there is a real danger that by talking about and focusing upon palliation, people may stop talking about and confronting the fact that the individual is going to die’ (Biswas, 1993,p. 135)

What would happen if hospice care vanished and was replaced by the broader more inclusive field of palliative care? Is there a trade-off involved between reaching a

wider patient population and explicitly addressing death and dying? Hospice care has a history of catering to those who are dying, and has developed expertise and professional tactics for dealing with questions related to dying. Even the name hospice performs a function, the name reminds patients that ultimately the journey they are experiencing ends in death.

Towards the end of my conversation with Charlie he brought up a tension that is at the heart of the hospice versus mainstream medicine and hospice versus palliative care debates. Charlie says, “Yeah, particularly the palliative I think I wish Hospice would expand their activity with the palliative, and give more attention to maybe curing people. But then Hospice wouldn't be Hospice, would it?” Here again Charlie betrays his uncertainty about what Palliative Care means, equating it with curative care, but he underscores the importance of hospice’s approach to dying.

What makes hospice distinctive and powerful is its niche in caring for the dying. Several hospice workers mentioned to me that they thought hospice would benefit from a “name change” so that it was not associated with dying. Marc, a spiritual counselor, mentioned that, “We almost need a name change.” He then characterized the hospice stigma as a consequence of “bad marketing”. When I asked him whether he thought there would be a problem with broadening the definition of hospice so that it is not just intended for dying patients his reply was, “You don't want to have them [patients and families] not face the real issues.” He recognized particularly strongly in his work as a spiritual counselor that facing, accepting, and preparing for death can be important tasks and hospice plays a role in fostering this work. Originally palliative care existed only under the bigger umbrella of hospice care. Now that palliative care is conceptualized as

the larger umbrella category (of which hospice is a subset) there is a potential for a remedicalization of the end of life experience.

The example of these two powerful institutions, Medicare and the medical profession, shows how they both expand and constrain patient autonomy and make patient decision-making more confusing. Although both Medicine and Medicare ostensibly provide patients with a choice, whether or not to start hospice care and whether or not to choose palliative care, these choices are limited by the physician's gatekeeping role. Moreover, the very meaning of "hospice" and lack of understanding about the meaning of "palliative" care further complicate patient choice.

Taking a step back I argue that the field of Medicine and the rules set by Medicare do more than influence participants choice in the field of hospice care. These institutional players shape how individual hospice patients and family members experience hospice care, but they also shape how we perceive and experience dying.

STUDY FINDING – MEDICAL IS SOCIAL

In this dissertation I argue that hospice care represents a case study of the scope and possibilities of medical decision-making. I contend that while scholars are good at theorizing about patient autonomy, and clinicians focus on a limited implementation of the principle, in practice patients and their families contend with a large array of decisions and numerous factors that enable and constrain their decisions. While previous scholars focus on the institutional factors, which largely constrain choice, I examine how social context changes decision-making.

This study finds that hospice participants are not only participating in a form of medical care they are making symbolic choices and a life decisions. I question some assumptions about medical decision-making, including the very assumption that some decisions are “medical” and others are not. In this section I review the study findings, the limitations of this study, and implications for future research and the provision of health care.

In Chapter 1 I make the case that the sociological gaze has been prone to a form of tunnel vision with respect to research on patient autonomy and medical decision-making. I contend that in order to observe the breadth of decision-making and the diversity of forces constraining and enabling patient autonomy it is necessary to change the focus and method of research. I argue that home hospice care is the ideal focus for research because (1) hospice care is conceptualized as a “choice”, (2) hospice care provides institutional care at home, (3) hospice care involves a range of social and medical decisions, (4) hospice provides care to patients and their family members, and (5) hospice care involves a critically important social and medical process – dying. Using a mixture of observation and interview methods enables this study to record the spoken and unspoken aspects of hospice care.

In Chapter 2 I review the history and philosophy of the hospice movement and how it was conceptualized as a response to excessive medicalization and patient objectification. I provide evidence that hospice represents a social decision by discussing evidence of its social meanings according to study participants. A dominant meaning among participants in this study cast hospice not as a strategic form of medical care, but as “choosing dying”. Meanwhile a subordinate meaning emphasized hospice’s positive

traits and ability to improve quality of life, viewing hospice as “about living”. In both cases the psychosocial meaning of hospice care overrides its medical connotations.

The social meanings of hospice prove to be powerful influences on the transition to hospice care as revealed in Chapter 3. Patients’ recollections of physician referrals to hospice reinforce the idea that most interpreted the decision to begin hospice care as more a commentary on their status as living or dying than as a specific medical intervention. Some patients portrayed their physicians as abandoning them or giving up on them in the process of referring to hospice. In many cases patients and family members take an active role in the referral to hospice care, either by self-referring, or by refusing or delaying hospice care. In this chapter it is clear that patient agency is complex and includes a comprehensive view of all interventions as being both social and medical.

In Chapter 4 I discuss the social context that influences decisions made in the course of hospice care. I find that the patient’s family circumstances, including the family’s financial situation, are often important determinants in decision-making. Also relevant to the types of decisions hospice care patients make are their beliefs about dying, and their religious or spiritual orientation. This individual level social context is critical to decisions as disparate as whether to use diapers or a catheter to whether to choose palliative sedation. Although many hospice care decisions superficially appear to be about medical interventions, many are in fact a balancing act between familial, financial, lifestyle, philosophical or spiritual, and medical concerns.

In Chapter 5 I portray how hospice as an institution, and hospice workers in their interactions with patients, are a demedicalizing influence that prompt all participants to think about hospice care decisions as inherently social decisions. A big component of

hospice care work consists of non-medical tasks, such as what hospice workers refer to as “normalizing” or “socializing” patients to dying. Much hospice work falls under the umbrella of holistic care and involves social, emotional, spiritual, and administrative tasks. Hospice workers refer to many of these tasks, such as saying good-byes and making “final arrangements” (mortuary and funeral planning) as “unfinished business.” I argue that focusing on these tasks leads to hospice workers facilitating patient autonomy, since many of these tasks are subjective and depend on patient preferences. Although hospice workers do sometimes oppose patients’ preferences, they are adept at enabling patients to make decisions.

In this final chapter I discuss the influence of external institutions such as Medicare and the medical profession, which have a mixed influence on patient autonomy. In some ways they open up new choices for patients, as in the creation and funding of the fields of hospice and palliative care, in other ways they force patients to make painful choices. Medicare, the medical profession, and hospice itself not only provide bureaucratic structure to a health care industry, they categorize people as living and dying. They are directly changing how we as a society perceive death and dying. They accomplish this through how they define, regulate, and justify hospice care.

MISSING VOICES: LIMITATIONS OF THIS STUDY

While this study encourages a new perspective on medical decision-making, it does not claim to be representative of hospice care in the United States or of hospice care patients as a whole. An overview of the limitations of this study suggests future areas of

research and sources of possible variation. There are four sources of bias which may skew these findings: (1) Pacific Hospice is a case study and may differ from other hospices in significant ways; (2) Sample bias limits this study to a self-selecting group of patients; (3) the focus on hospice care patients ignores the group of patients who were never referred to hospice; (4) also missing are the stories of patients who were referred to hospice but declined hospice care.

Not only is this study intentionally limited to *home* hospice care, excluding the many Pacific Hospice patients living in nursing homes or temporarily residing at the inpatient hospice center, but it also focuses on a specific type of hospice. Hospice organizations differ in size, non-profit or for-profit status, location, philosophy and organizational model. Pacific Hospice is a large non-profit hospice⁵⁴ in a metropolitan area. Research on the experience of inpatient hospice care suggests that it is a markedly different experience than at home care (Broom and Cavenagh 2011; Lawton 1998). The experience of patients in for-profit hospices also may be quite different with patients in for-profit hospice receiving fewer services and less holistic care (Carlson, Gallo, and Bradley 2004) and for-profit hospices may select patients to enroll who are more profitable for them (Lorenz, Ettner, Rosenfeld, Carlisle, Leake, and Asch 2002; Wachterman, Marcantonio, Davis, and McCarthy 2011). I do not argue that this case study of hospice care is representative of hospice care as a whole, only that it is one

⁵⁴ Industry wide changes are evident in this area. When I was planning this research not-for-profit hospice organizations were the most common. In 2006 NHPCO estimated 49% of hospice organization were not-for-profit and 46% were for-profit. National Hospice and Palliative Care Organization. 2007. *NHPCO Facts and Figures: Hospice Care in America 2006*. By 2011 when the study was completed the respective percentages were 30% not-for-profit and 60% for-profit tax status. —. 2012. "NHPCO Facts and Figures: Hospice Care in America."

example which is instructive because it highlights some aspects of the hospice experience that are under-acknowledged in research on hospice care (i.e. home care). This case study does not provide any evidence about the frequency of trends explored in this study it simply provides evidence of their relevance to the lives of participants in this study.

The sample of patients included in this study was constructed to achieve narratives of extensive experience of home hospice care, but it contains several sources of bias. The sample contained no patients younger than 70 and no racial or ethnic minorities. Study patients were on hospice for longer than average lengths of time, which improved their ability to experience and discuss hospice services, but is not representative of the greater hospice patient population. Indeed some of these patients, like Cliff, Gene, Judith, Steve, and Jerry referred to themselves as “beating the odds” either because they lived so long or they “outlived” the doctor’s prognosis. While many of the patients in this study are outliers in terms of the length of time they lived after beginning hospice care⁵⁵, they are the ideal study population since they have had ample time to sample the range of end of life care options and are still alert and able to communicate about this process. What

⁵⁵ It is difficult to measure exactly how long people live after beginning hospice care. Many people are either discharged from hospice still alive, or survive more than a year. In 2010 these numbers were 16.4% discharged alive, and 18.5% carried over from the previous year. However the NHPCO gives us some approximation: 35.5% patients receive hospice care for less than 7 days, 27.0% for 8-29 days, 17.2% for 30-89 days, 8.7% for 90-179 days, and 11.8% for 180 days or more. While it is surprising how quickly some patients die, a problem sometimes labeled “late referrals”, given the fact that many patients reported believing hospice meant you would be dead within days or weeks, it is important to point out that a large number of patients received hospice care for more than a month after referral to hospice 37.5%. No doubt true survival percentages are larger because many patients are discharged from hospice in order to go to a hospital and then are re-admitted to hospice at a later date. Carlson, M. D., W. T. Gallo, and E. H. Bradley. 2004. "Ownership status and patterns of care in hospice: results from the National Home and Hospice Care Survey." *Medical Care* 42:432-438.

these participants' stories and national statistics tell us is that for any one individual dying can be very unpredictable and even doctors' prognoses are a poor indicator of outcomes.

As in other examples of ethnographic research and particularly because of the vulnerability and instability of patients enrolled in this study the participants in this study are a self-selecting group. Patients and family members who enrolled in this study are probably different from those who did not enroll. First, strict inclusion criteria meant that patient participants were all adult, English speaking, and perhaps most importantly physically and mentally able to participate in interviews. It is likely that these criteria excluded patients with the most severe illness symptoms. This bias is important because it is likely that as a group patients who were more physically limited would care more about and be more concerned with the medical aspects of hospice care and be less able or interested in participating in some of the non-medical and holistic hospice care tasks. However, my sample shows that even patients who are severely physically compromised, like Dottie who is bedbound, can request and value a range of non-medical services provided by hospice.

The patients enrolled in this study are self-selecting in the sense that they are likely to be the kind of people interested in participating in a research study at what they know to be the end of their lives. In my assessment the patients enrolled tended to be outgoing, personable, loquacious, and altruistic in the sense that they wanted to help other hospice patients (and help me) by enrolling in a study which they believed would serve the common good. There is no real alternative to this type of bias in a study such as this, since the researcher must to be invited into family homes. It is also relevant that these patients as a group had a very high opinion of hospice care in general and Pacific Hospice

in particular. They also tended to live with or have family members who were generally in sync with their wishes and beliefs. I hypothesize that patients who feel negatively toward hospice, have strife within their family, or who have family members who are negative or suspicious about hospice care would not wish to ask a researcher to visit their home to discuss hospice. The same tendencies applied to the family members and hospice staff participating in this study, they tended to be in good health, enthusiastic about hospice care, and have outgoing personalities.

This research study is unable to represent the full range of decision-making about hospice care for another reason. Missing from this analysis are the voices of two core groups of patients who are currently understudied: patients who are never referred to hospice, and patients who are referred but do not enroll. Christakis has provided a good taxonomy of the reasons physicians avoid referring patients to hospice care (1999). In the case of patients who are referred but do not enroll in hospice care, there are both social and medical/logistical reasons patients resist hospice care (Vig et al. 2010). Vig et al suggest that caregivers often play a powerful role in deterring patients from accepting hospice care, a phenomenon I heard many references to in this research study. A hospice spiritual counselor, Marc, explains why he thinks family members often resist hospice more than patients themselves.

Something I've come to believe in my work fairly strongly and that is that those who are dying tend to be more ready for it than those around them. And they come to terms -- but it's in their body. They've dealt with it from the beginning where -- and their family for so long has spent the time probably saying don't worry, it will be okay, trying to minimize and deny it, and to do that they have to do it for themselves. And they don't know what's going on in the body and they're not the one going through all the treatments that suck. You know I'll hear from patients like I want to be done with this, but I'm afraid how my family will respond. And there's

guilt for saying you know I want to go on hospice. I want to give up. I don't want to take that damn chemo anymore. So oftentimes they are way ahead of these caregivers...

Marc implies that family members often push for more aggressive treatment. Just as caregivers can be instrumental in working to help patients begin hospice care, they may equally well work to prevent some patients from receiving hospice care or lead them to seek hospice care only when death is imminent, contributing to the phenomenon of “late referrals” to hospice.

Also missing in this analysis are the voices of patients who enrolled in hospice care, but did not have a “choice”. One exception was the story of Gunnar an 80 year old man with Cirrhosis who lives in a board and care home and has a “private fiduciary” managing his financial and medical affairs as a consequence of his long history of alcoholism. Gunnar explains that it was the private fiduciary who decided he should start hospice care. In other more common instances, patients with Alzheimer’s and dementia often have little input into the decision to start hospice care, relying on family members or in their absence other authority figures. As diagnoses like Alzheimer’s and Dementia currently amount to 12.5% of all hospice patients nationwide (National Hospice and Palliative Care Organization 2012), it is likely that appointed legal guardians and conservators are often the primary decision makers deciding when and if to start hospice care. In many other cases patients are either unable to communicate or unconscious when they are referred to hospice and it is their family members or guardians who are instrumental in deciding to start hospice care.

Despite the pertinent limitations of this study I suggest that its findings with respect to the social context of medical decisions and the relevance to patient autonomy are valuable contributions to three separate arenas: (1) the field of hospice care, (2) the wider field of health care, and (3) social beliefs about dying.

IMPLICATIONS FOR HOSPICE CARE

This study provides a firsthand account of patient, family members, and hospice staff experiences with hospice care. Much of what this study reveals will be familiar to hospice care professionals, some insights may be new to them. Beginning with the act of referral to hospice care this study portrays the gamut of patient experiences from very negative to extremely positive. In Chapter 3 it was observed that the patients who were most likely to self-refer and to support the idea of hospice care were those who had already had a prior experience with a family member in hospice. Social reproduction not only explains how children learn to live, work, and interact with others (Lareau 2003; Willis 1981), it explains how adults learn to die. This pattern suggests that to reduce the stigma of hospice and encourage more people to use hospice services trusted sources such as family members and friends may be the best educators. The evidence from this study suggests that exposing people to hospice care is the key ingredient to its continued success and expansion.

Although most of the literature on referral to hospice focuses on the role of physicians, this study shows that patient perceptions of physician referrals are often quite negative. Patients often felt abandoned by physicians who referred them to hospice and

experienced the referral as a very negative form of demedicalization. The few patients who described physician's referrals in a positive light provide an instructive example of how physicians might persuade patients that hospice is an important medical and social intervention that may improve their lives.

With respect to the provision of hospice care this study highlighted some of the variability in how patients and their families respond to decision-making in hospice care. This study exposes key social factors that influence both patient (or family member) decision-making and the very issue of whether they desire to make decisions. These social factors include prior knowledge or experience of hospice, family considerations, financial circumstances, beliefs about dying, and religious or spiritual beliefs.

IMPLICATIONS FOR HEALTH CARE

I contend that the most important implications of this research apply to the broader field of health care. Although I discuss decisions made in the context of hospice care, many of the exact same or similar decisions are made outside of hospice care. The study population of hospice care patients was selected as one that would have bearing on the wider category of medical decision-making. Palliative sedation, whether to use a catheter or adult diapers, what medications to take, what to tell medical professionals, whether to hire a home health aide to help with bathing, and whether to use medical equipment like hospital beds are all issues which can arise in cases of chronic illness, and in cases of patients with terminal illness that do not enroll in hospice care. Patients like Cliff who are reluctant to ask hired caregivers to help with intimate tasks (such as placing

a bandage on his tailbone) and patients like Dottie who are embarrassed to have an adult son assist with toileting and bathing exist in and outside of hospice care. Research in hospitals obscures some of these dynamics so important in the home setting. This research shows how vital and complex these decisions are for patients.

This study also suggests how to improve care for all patients throughout the health care system by focusing on how medical decisions are presented to and received by patients. Patients and family members in this study are often focused on the broader concerns of the illness. Their concerns are often psychosocial and in this sense their experience is a demedicalized version of what clinician based research finds. It is demedicalized in two essential ways. First, patients and family members themselves inherently view their experiences as not only a medical event but a psychosocial process, what Bury referred to as a “biographical disruption” (1982). Second, hospice as an institution has a demedicalizing influence. Hospice as an institution and its workers as representatives of that institution tend to focus on illness experience and the question of how to enhance quality of life. Since *curing* is off the agenda for hospice patients we see how institutions can focus on *caring* as a goal in itself. When *care* is the goal, patients more readily become decision-makers, as they are the best experts on how to improve their own quality of life.

Critics may argue that hospice is unique in its focus on caring and lack of attention to curing. I argue that for a growing segment of the health care field caring and improving the illness experience is its mission. I argue that this is not an example of medicalization of caring, but instead of a shift in the work of medical care so that care is a primary concern. With the epidemiological shift from infectious disease to chronic

disease the bulk of health care work has also shifted from *curing* disease to *caring* for illness. The task of caring includes a range of services from the custodial care of nursing homes to the psychosocial care of grief counselors and support groups. Nursing homes are primarily oriented around providing long term care to patients. The growing demand for home health aides reflects a desire to have in-home help. These home health aides' primary purpose is to maintain patients health by helping them with daily living tasks. The aging American population combined with the increase in people living with chronic illnesses, many of which can not be cured, means that as a field medicine increasingly needs to focus on how to maintain health, reduce pain, and increase quality of life. With respect to conditions as diverse as diabetes, dementia, Rheumatoid Arthritis, epilepsy, stroke, and some cases of heart disease and cancer the primary goal of medical treatment is to reduce symptoms (as in palliative care), prevent the disease from worsening, and improve quality of life.

For health care professionals understanding the social context of patients' decisions muddies the concept of compliance and non-compliance to provider recommendations (Conrad 1985). The familial, financial, psychosocial and spiritual, factors in patient decision-making exposed in this study may allow health care professionals to reassess or revise the recommendations they are making to patients. If patients are not filling their prescriptions or attending follow-up doctors appointments this study suggests some possible reasons that providers can incorporate into their strategies. Perhaps the patients can no longer drive to the pharmacy or doctor's office, perhaps they can not afford the co-pays for all their medications, perhaps they are simply overwhelmed by the administrative task of coordinating medications and doctors'

appointments. Indeed hospice patients repeatedly told me that some of the features they valued most in hospice were the facts that it covered the cost of medications, would deliver medications to their homes, and that they no longer had to schedule and attend myriad doctors' appointments. Enabling physicians and other health professionals to see the patient's perspective on these social and medical decisions is one the goals of this research.

While this study suggests how we can work toward improved patient, it also exposes some of the threats to this progress. My discussion of Medicare and the role of the medical profession highlights that they have a very large impact on the future of hospice care and consequently on the ability of patients to control their end of life experience. These institutions not only grant choices they can restrict choices, and as pressure within the United States mounts to find a way to make health care more cost-effective it is likely that costly end of life care and care for chronic illnesses will be the target of stricter regulations about when and what choices patients can make.

CHANGING SOCIAL BELIEFS ABOUT DYING

This study is not only about hospice care, nor is it limited to health care as a field. The example of Pacific Hospice and the stories told by patients, family members, and other hospice staff demonstrate how it is our very definition of living and dying that is changing. The social meaning of hospice is so powerful because hospice as an institution is not simply a medical entity it is also a code word for dying. The historical emergence of hospice care has changed our perception of and reaction to dying. In this case study

Pacific Hospice illustrates the ambivalence people feel toward hospice. Because hospice is stigmatized and associated with “choosing dying” many participants resisted beginning hospice care. Most that began hospice care were forced or chose to address the idea that they were in fact close to death.

Patients who refuse hospice care as not likely to have their prognosis change. They will most likely die at approximately the same time whether they begin hospice care or not. However, they perceive hospice as choosing death and in some respects they perceive mainstream medical care as choosing life or choosing to fight. By decreeing that hospice patients must have a prognosis of six months or less and must forego curative care to enroll Medicare cementing an arbitrary definition of dying.

While Medicare fosters some stigma about dying via its regulation of hospice care, hospice care itself does much to change social norms about dying. The hospice philosophy was meant to tackle and change the social stigma about dying and to demonstrate how accepting dying could improve individual experiences. Although the majority of the work that hospice participants do to prepare for dying is related to the death of the hospice patients, all this work leads other participants to begin to think about and plan their own end of life experiences.

Hospice workers sometimes foster this expansive approach to dying. In a notable example while Ellen, a hospice nurse, and Doug are discussing care for Doug’s mother Dottie the conversation gradually shifts to a discussion of what will happen to Doug as he ages. The conversation begins with Doug asking about respite services and explaining that his mother is afraid of nursing homes (Skilled Nursing Facilities - SNFs) and would

probably be unwilling to go to one for respite care. Here is an excerpt from my field notes:

Doug and Ellen mention that finding a bed can be tough at the SNFs. At one point Doug mentions that he does not care what happens to him when he gets to the point his mother is at, he would be fine to go to the nursing home. He says nursing homes are going to have a real problem when his age group gets there because of the baby boom. Ellen says that he might care when he gets to that point. Ellen asks if he has long term care insurance/disability insurance. Doug says no. Ellen is very deft at steering the conversation to him, a guy who clearly does not like to talk about himself much. Ellen mentions that his mother, Dottie, told her what her plans were for her property (suggesting that it was partly to go to certain charities and the rest to Doug) and that he should remember that he could use his inheritance to pay for a caregiver for himself. (Doug seems perfectly healthy at this time, but Ellen appears to be educating him about his own future). Ellen gestures at the house, which is not in very good shape but which is on prime real estate in a beach neighborhood and would probably fetch a very high price for the lot alone. (Field notes 8/12/2011)

Hospice as an institution is not only helping its patients cope with their impending death, by extension it is helping family members to think about their own expectations and plans for the end of life.

Not only do hospice workers educate patients and family members about dying, but also as many hospice workers noted the process works in reverse. Through observing and listening to patient and family members' experiences hospice workers including volunteers find their own beliefs about dying changing. Hospice workers often consider hospice work as a "calling" and hope for a social change in our approach to dying. Some hospice workers, particularly volunteers, are drawn to hospice work because they have fears or a curiosity about dying. Christina, a volunteer who practices Reiki and energy healing with hospice patients explains why she chose to volunteer. As part of her own

path to becoming an energy healer, her teacher went through sessions with her geared towards what Christina describes as “healing the healer”.

But basically a lot of the things that we went through when we working on my life dealt with grief and loss and in fact, my mother died when I was seven and it was a situation where we were expecting a new baby and she went to the hospital and had the baby and then she never came back. It was—at that time, we never saw her deceased body. We never saw—we never went to the funeral. We never had any kind of closure or anything about that. And so I sat on these things for over 50 years, which were really minimizing my enjoyment of life without my realizing it even... So it was—so I say a lot of the things we went through before that I was taking—it kind of, to me, was abandonment more than anything else and rather than a healthy grief, it was more of a feeling that I was somehow at fault because that’s how she left. The whole time—the whole thing was a trip that I had had. While I was successful in life and I was doing just fine teaching and all of this other stuff, I never realized that I wasn’t really living life thoroughly but I was dividing life, that’s what I did. And a lot of it was centered on that and so I thought when I was talking to him that this [volunteering] might be really helpful for me to deal with death and all of that in a healthy manner and to really see myself there.

Christina is like many hospice workers in that she had a very personal reason for joining Pacific Hospice, to explore her own attitudes toward dying. In this sense hospice is a vehicle for changing social beliefs about dying. In many ways the example of Pacific Hospice and its patients shows that to an extent that goal has been realized, hospice care has introduced and popularized an approach to dying that changes patients experiences. Hospice was intended to be a demedicalizing influence focusing on improving patient quality of life. Some of its success in providing care to dying patients arises from hospice setting itself apart from mainstream medical care, however this distinction may be blurring.

Although its future is uncertain hospice care is still a growing phenomenon in this country (National Hospice and Palliative Care Organization 2012). Judging by the growth of hospital-based palliative care it seems as though the division between hospice and the rest of mainstream medical care is breaking down. As Cicely Saunders suggested, “There is absolutely nothing in what has been achieved in the hospice movement which could not apply to the broadest aspects of health care. Hospice care is a misnomer when applied only to the dying patient and the issues surrounding death. The next thirteen years ought to focus on the expansion of the hospice concept with the aim of making all illness and its treatment the focus of attention of the hospice approach” (1980, 6). As this research suggests hospice care is valuable and meaningful to patients in part because of its focus on the social causes and consequences of medical decisions. Hospice care illustrates how disentangling social and medical decisions is easier in theory than in practice. As Saunders suggested, these principles can and should apply to the broader field of health care. Depending on which direction the field takes now, palliative care in hospitals might subsume hospice palliative care, or hospital palliative care might bring hospice principles to the wider field of medicine. We are waiting to see whether current changes will bring a fulfillment of Saunder’s prophecy or a re-medicalization of dying.

APPENDIX. NOTES ON METHODS, FIELD RESEARCH, AND ETHICS

PRACTICAL AND ETHICAL CONSIDERATION IN HOSPICE RESEARCH

I was fortunate to have invaluable assistance from Pacific Hospice in recruiting patients to this study. Through their guidance and my own process of trial and error I learned much about how to conduct research on a vulnerable population such as these hospice patients and their family members. For this research it was critical that I have support from the Pacific Hospice staff and in particular clinicians such as nurses who could determine which patients met the mental and physical criteria for the study (specifically they needed to meet my IRB approved inclusion criteria). Due to Pacific Hospice's valid concerns about giving me access to patient information, their employees screened patients for me and forwarded me the names, phone numbers, and summary information for patients interested in participating in my research. I found that trying to recruit family members over the phone was more difficult. Often the family members included in this study were either present at the patients' home so I could meet them face to face, or I contacted them after interviewing the patients.

Similarly with hospice staff, I found that once I told hospice workers that the patient was already enrolled in the study many were willing to include me in their visits with that patient, allowing me to observe. When I first began planning this research I believed that it would be easier to recruit hospice staff and more difficult to recruit

patients. However, paid hospice staff, were often the hardest to contact and often did not have time for long interviews, or any interviews. Patients, family members, and volunteers generally had more disposable time and were easier to include in the study.

Prior to beginning the research ethical considerations were paramount in my planning of what questions to include in my interviews and how to write my IRB application. Following the example of other scholars my plan was to try to talk about dying without using the words “death” or “dying.” In practice it quickly became clear which patients wanted to talk about dying (either using that word or using some euphemism). Patients who wanted to talk about dying did so with no prompting. Patients who do not wish to discuss dying avoided the topic in an obvious way. I was still careful to avoid using words like “death” and “dying”, unless patients or family members asked me direct questions about these topics.

Patients reported enjoying the interviews and appreciating the chance to tell their stories. Most patients were also willing to have me do observation of their hospice visits, appreciating how this would provide a better overall picture of what the hospice care experience is like for patients. Family members who had the time were also often appreciative of the chance to do an interview, particularly private interviews in which they could voice some of their personal thoughts about caregiving.

In general I found the hospice patient population, although “vulnerable” by IRB standards, to be self-selecting in such a way that the patients included in the study were the least likely to experience any negative consequences from participation. Only patients whose health was relatively stable health were candidates for interviews. On several

occasions a patient's health worsened before I could schedule an interview and they were never able to participate in the study.

The unpredictability of the hospice patient population was one reason I was advised to and found it of critical importance to proceed very quickly. Patients might be willing to meet with me one day and be hospitalized or dead the next. I generally set up interviews for within a day or two of my initial phone conversation with subjects. When possible and desirable I did follow-up interviews with patients or their family members. It was also crucial for me to try to remain a positive but neutral presence. I always met with patients in their homes. Sometimes they were reclining in bed, sometimes sitting in big armchairs. They often asked me what I thought about hospice and I tried to deflect their questions and return the topic to their own opinions.

It was also common for patients to ask me what other patients were like and how they compared to them. Hospice patients in their own homes had no contact with other hospice patients. While some illnesses provoke health social movement based on identity, patients at the end of life are largely insulated from other similar patients. They rely on hospice workers and family members to share their experiences. For many of these patients, and some family members, dying was a lonely experience. They were often no longer able to walk or drive and were confined to their homes and only exposed to people who came to visit them. For patients like this hospice was not only a form of medical care, it became their social world. Often the hospice workers and volunteers were the primary links between patients and the world outside their homes. Sometimes hospice workers were a patient's only social world (when family and friends were deceased or absent).

EPILOGUE

As expected most of the patients interviewed for this study died soon after they participated in this research. Here is a quick summary of what happened to the patients in this study as of my last follow up with Pacific Hospice in May 2012.

- Cliff, the 89 year old with ALS who had no family but a hired caregiver, Lucia, died at home after receiving hospice care for 20 months (6 months after he began this study).
- Gene, the 77 year old Navy veteran with prostate cancer who lived with his wife, daughter and grandchildren, died at home after receiving hospice care for 4 months (2 months after he began this study).
- Judith, the 92 year old with a rare heart disease who lived alone, died at home after receiving hospice care for almost 7 years (two months after she began this study).
- Steve, the 71 year old with lung cancer who lived with his wife and his cat who also had terminal cancer, died at home after receiving hospice care for 7 months (4 months after he began this study).
- Dottie, the 94 year old with a diagnosis of Debility Unspecified whose primary caregiver was her son Doug, died at home after receiving hospice care for 14 months (3 months after she began this study).
- Henri, the 77 year old physician who lived with his wife Sandra, died at home after receiving hospice care for 7 months (3 months after he began this study).

- Gunnar, the 80 year old with Cirrhosis living in a board and care home, was discharged from hospice after 2.5 years when his prognosis was extended.
- Joseph, the 87 year old with Lymphoma living with his wife Joan in a luxurious assisted living facility, chose to end hospice services after almost 3 years and died the day after he was discharged (4 months after he began this study).
- Alice, the 88 year old with Pulmonary Fibrosis, died in her assisted living facility after receiving hospice care for 2.5 years (7 months after she began this study).
- Florence, the 98 year old with cardiac disease living in her daughter and son-in-law's home, died at home after receiving hospice care for 1.5 years (6 months after she began this study).
- June, the 89 year old with Debility Unspecified, died in her board and care home after receiving hospice care for 11 months (1 month after she began this study).
- Carolyn, the 72 year old with COPD living in an apartment with her husband Samuel, died in the hospice inpatient facility after receiving hospice care for 10 months (1 month after she began this study).
- Charlie, the 86 year old with Debility Unspecified living with his wife with dementia and caregiver Rhonda was still alive after 1.5 years of receiving hospice care.
- Rose, the 90 year old with COPD living with her adult son Nathan, was still alive after almost 4 years of hospice care.
- Jerry, the 80 year old former golf professional with COPD living with his wife Deborah, was still alive after almost 3 years of hospice care.

- Dana, the 79 year old with lung cancer living alone in a mobile home, was still alive after 9 months of hospice care.
- Joyce, the 72 year old with COPD living with her husband Tom, was still alive after 5.5 years of hospice care.
- Rachel, the 96 year old with a diagnosis of Debility Unspecified who was living alone but receiving help from her hired caregiver Isabel, was still alive after 16 months of hospice care.

INTERVIEW SCHEDULES

The following interview schedules were used more as starting points than as fixed scripts for interviews. The interviews in this study were informal and semi-structured. I began each visit with a patient by going over the goals of the research and consent forms. I then asked a general question intended to be an ice-breaker that would reveal some background information about that person and allow them to feel more comfortable with me. I usually began by asking them to tell me about their personal background, or in some cases by asking them to tell me the story of how their illness began. Often something in the house or immediate environment would trigger the first question, for example a family photo on a side table or a book lying on the coffee table. Hospice staff often had a shorter window for interviews and were more comfortable talking about hospice and dying, so typically my first question for them would be “How long have you worked with hospice and how did you start doing hospice work?”

The interviews progressed more as conversations than as strict interviews. I tried to steer the conversation to topics that were important to my study, such as learning their thoughts about hospice, medical care prior to hospice, etc. However, often I was be surprised by the turns conversations took and some of the most powerful stories I heard were the result of digressions in our conversations.

Patient/Family member interview questions

1. Can you tell me about when your (or your family member's) illness began?
2. How did you first hear of hospice?
3. Have you ever had (another) family member or friend in hospice care?
4. How did you get referred to hospice?
5. Did your family members (or you) participate in the decision to start hospice care?
6. What do you think about hospice care? What hospice services are most important to you?
7. What do you think is the goal of hospice care?
8. Can you tell me about your experiences with medical care for your illness before you (or your family member) started hospice care?
9. How do you think hospice care compares to the type of medical care you (or your family member) were receiving before you began hospice?
10. Can you tell me a little bit about yourself and your personal background?
11. Do you have any family? Have they helped take care of you (or your family member) during your illness?
12. Were you employed before your illness began? (If family member: Are you currently employed?) What type of job did/do you have?
13. Do you consider yourself to be religious?

Hospice staff/volunteer interview questions

1. What is your position at hospice? How long have you worked/volunteered for hospice?
2. How did you decide to work/volunteer for hospice? What was your previous work experience?
3. Do you think hospice care has changed since you started working here?
4. How did you first hear about hospice care?
5. Have you ever had a friend or family member in hospice care?
6. What do you think patients and family members find most valuable about hospice care?
7. Do you think hospice changes the experience of dying for patients and their family members?
8. If so how do you think hospice changes the experience of dying?
9. What do you think is the goal of hospice care?
10. Sometimes people use the phrase “good death” to describe certain ways of dying. Do you think there is such a thing as a “good death”?
11. If so what does a “good death” mean to you?
12. Do you see differences among patients in how they feel about hospice care?
13. If so, what do you think might cause some of these differences? (e.g. level of pain, diagnosis, family status, age, race/ethnicity, culture, gender)
14. Based on your experience do you think that the relationship between patients and their family members has a big effect on their experiences with hospice care?
15. For example do you think having family members helps patients receive better services?

16. Does having family members ever create problems in providing hospice services?
17. Do the patients and the family members ever disagree about what they want?
18. Can you tell me a little bit about yourself and your personal background?
19. Do you have any family?
20. Do you consider yourself to be religious?
21. Are you currently employed?

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