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**The Relationship Between the Physician and the
Dying Patient: A Qualitative Analysis**

by

Ori [Tzvieli]

B.A. (University of California, Berkeley) 1994

A thesis submitted in partial satisfaction of the

requirement for the degree of

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in

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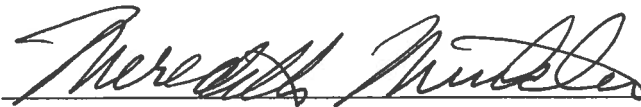
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Preface

Writing this thesis has not been an easy task. I write this preface on the fifteenth of February 1998, with my thesis yet unwritten, as procrastination to the writing of actual content. I trust it will find its way to the final document.

I'm not comfortable knowing I will one day be an allopathic physician. I want more than what we've been trained for so far — more time for meaningful human contact, more non-harming interventions, and more holistic diagnostic skills. In a sense, the struggles of getting to my thesis topic is a struggle to supplement what I've been taught, an attempt to find a piece of something I want to learn and am not getting through my classes.

Fundamentally, I want to learn a medicine more motivated by trust than by fear. Intuitively, I know that there is no greater teacher in those two emotions than death. What I really want is to learn to sit with dying people. But as my committee's chairperson Dr. Andrew Scharlach put it in our first meeting: "It sounds good, but it doesn't sound like a thesis." So I'm trying to build a thesis around that desire, with the hope of learning to trust the processes of health and illness more profoundly. I hope that the impact of this research project on me as a future physician will be much deeper than the conclusions found in the pages ahead of you. I hope that you as a reader can find meaning and value in what you read, and that it will touch your heart.

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Introduction – The Context of Death in America

*And come he slow, or come he fast,
It is but Death who comes at last.*

Marmion

Sir Walter Scott, 1805¹

As we near the changing of the millenium, our society continues to get older. The average life expectancy at birth today stands at 76, compared with 47 at the turn of the century². Yet despite the immense progress in medical technology and public health that allows us to live longer, inevitably we all must face death. As we grow older, the reality of physical change reminds us not only of our social position as elderly but also of the impending loss of our physical body, offering a chance to explore the very essence of our being. The process of dying, therefore, can be opportunity for spiritual and emotional exploration and perhaps even transformation. In contrast, our society's reality of death is often one of technological dependency, noise, chaos, and lack of social support. Death in America is highly medicalized and still takes place in institutions, mostly hospitals and nursing homes. Within this actuality, dying often involves substantial interaction with health-care practitioners. It is precisely this relationship that my thesis project seeks to explore. In this introduction, I will outline the epidemiological context of death in the United States today – outlining how my research fits into the continuum of possible settings for dying people.

The Epidemiology of Death – When, Why and Where We Die (And How Much it Costs!)

The total number of deaths in America in 1997 was estimated to be slightly under 2.5 million or 1% of the overall population. This percentage reflects a significant decline in death rates over the past century. Quantitatively, the age-adjusted death rate has been reduced from 1076 per 100,000 in 1940 to 503 per 100,000 residents in 1995. Women have benefited from the decreased death rate and increased life expectancy more than men, with the average white woman currently expected to live to 79.6 years of age as compared to 73.4 for white men. Likewise, it is apparent that whites have benefited more than blacks, with the life expectancy of black women at 74.0 years and black men at 65.4 years. The Institute of Medicine attributes the majority of improvements to a reduction in child and infant mortality, leading to 73 percent of deaths occurring amongst those of age 65 and over nationally³. Death has clearly become an event that primarily occurs in what many would call old age³.

An examination of why Americans die is at once a testament to the many advances of modern medicine as well as an indictment of the disparities that characterize life for various racial groups in America. Heart disease, cancer and strokes (in that order) have replaced the infectious diseases as the most common causes of death in the United States today. These three causes account for 67 percent of overall deaths for those of age 65 and older. Americans, in general, die sick. However, for black males in 1993, “homicide, HIV infection, and unintentional injuries precede stroke as the third, fourth and fifth leading causes of death. After heart disease and cancer, Hispanic males were most likely

to die of unintentional injuries and HIV infection.”³ Only for Native Americans does suicide rank in the top 10 causes of death. It is unclear if these racial differences hold true within the elderly population (65 and over).

Over the past century, death has moved out of the home and into institutions. By 1980 three-fourths of all deaths occurred in institutions, mostly hospitals. However, government and private insurance coverage of hospice care and a Medicare compensation method that discouraged inpatient hospital stays (all of which began in the 1980s) began to reverse this trend and increased the proportion of people dying in homes and long-term care facilities. In 1992, 20 percent of people died at home and 57 percent died in hospitals (the vast majority in inpatient wards). The remaining people died mostly in nursing homes (17%) or elsewhere (6%). The Institute of Medicine projects that the trend will continue to reverse in the late 1990s³. Amongst the very old (85 years and over), a greater number die outside of the hospital. The data on actual place of death remain weak, and considerable variation from state to state is the norm. The information on where people spend the last few months of life is even sketchier. For example, the statistics above do not capture the experience of older folks who are transferred from a nursing home to the hospital in order to die, or vice versa. About 17 percent of the people who die in America today receive hospice care (see below), for which they are eligible if they have a life expectancy of 6 months or less³. Approximately 71 percent of hospice patients are elderly. The population of individuals eligible for hospice is expected to increase as the population of the United States ages⁴.

The reasons that the setting for the last months and weeks of life has shifted away

from the home are multifaceted. The breakdown of the extended family as a living arrangement in this century has created more empty homes, where no caretaker is available because of the need to work for financial necessity. Improvements in medical care have shifted attitudes in American society leading to a perception that death can be more successfully prevented or delayed through the use of technology. This reality has corresponded with the rise of the hospital intensive care unit and “911” emergency services which bring people into hospitals and track them into an institutional care setting. In addition, the changing technological, geographic and financial infrastructure has made home visits by physicians less common. Once death moved away from the home, people became less acquainted with its realities of it. The void thus created allowed for more fear and uncertainty set in and was often filled by technological and institutional presence in our culture.

As death has come out of the home, it has gone “into the closet.” McCue argues that this change is probably irreversible for a reason independent of physicians’ attitudes:

...it is unlikely that we will, as a society, decide to take our dying elders back into our homes. We seem to tolerate the sights and smells of dying less well than was the case earlier this century... The expectation of the use of at least minimal medical technology at the time of death, such as intravenous fluids and oxygen, may or may not be rational, but it can cause families to feel neglectful of elders who might be denied such technology if they die at home.”⁵

The need for social acceptance of death outside of the hospital is further elucidated by Seamark, whose British study points to a sizeable minority of cases (between 10 and 30 percent) in which physicians would have preferred their patients to die in hospice or at home had such services been available and the families willing⁶.

The issue of the cost of health care at the end of life has important ramifications for quality of life in the dying process. Decisions based on financing can affect the mix of services, providers and health-care settings available to individuals facing death depending on their insurance coverage or financial means. Nationally, the Institute of Medicine projects that over one-fourth of Medicare costs in the 1980s were spent on the 5-6 percent of elderly people in their last year of life³. Indeed, dying is to a large extent publicly funded through Medicare, Medicaid or Veterans and Department of Defense programs. About 10 percent of dying costs are covered by private insurance while beneficiary out-of-pocket spending pays 20 percent. Most of the out-of-pocket expenditures go towards covering long-term care, medications and supportive services, for which Medicare benefits are more limited. Terminal and chronic illnesses have significant financial consequences for the families of those who die, stemming in part from out-of-pocket expense but also from lower income which results from absenteeism, reduced working hours or job loss due to the need to care for the family member. Thus, the patient's family often shares the costs of dying³.

The "How" of Death in the American Elderly: Symptoms at the End of Life

Studies of the experiences of dying persons indicate a considerable commonality of signs and symptoms but also a sufficient diversity as to exclude a generalizing model of the death process. National data indicate common physiological signs of imminent death include visual and auditory hallucinations, irregular breathing, excessive secretions, cool extremities and truncal warmth, sleepiness and disorientation³. Three out of four patients

are nonambulatory on the last day of life, 40 percent have difficulty recognizing family and 55 percent are unable to eat. A third of patients report some pain on the last day of life. Deterioration and the development of these conditions generally takes less than a year. Anxiety and shortness of breath at the very end of life are also common (25 percent)³. When increasing the scope to the entire year preceding death, the following are the most common symptoms in decreasing order: Pain (72%), mobility problems (70%), trouble breathing (49%), loss of appetite (47%), Drowsiness (44%), Constipation (36%), Depression (36%), Vomiting/Feeling sick (33%), Dry Mouth (33%), Backache (31%). Simple effective methods exist for relieving many of these symptoms through medical management^{7, 8}.

In general, the older the patient at the time of death the more likely he/she is to experience mental confusion, incontinence, difficulty hearing and seeing, and disability in the activities of daily living. It is not surprising, therefore, that people who die older and at home had more problems with things such as toilets and stairs as opposed to those in residential care. People who die at an older age have their symptoms for longer but are much less likely to report their symptoms as “very distressing”, possibly because having had them longer, they may have gotten used to them. In general, people who die older have greater needs but less support from relatives and medical and nursing care in relation to their needs than individuals who die at younger ages⁹.

Social and Medical Attitudes towards Death

Perhaps more than any other developed country the United States has exhibited a

passion for attempting to conquer death, often acting as if it is one more disease to overcome. Medical practice has not been free of this attitude. As Callahan says, the “practice of medicine, moreover, has come to treat death as a kind of accident, a contingent event that greater prevention, improved technology and further research could do away with.”¹⁰ This belief has historical roots in the mid-19th century, with the emergence of the scientific paradigm and the germ theory of disease in American medicine^{11, 12}. Indeed, National Institutes of Health Research grants are disproportionately distributed towards those diseases that cause death as opposed to those that reduce or destroy quality of life¹⁰. Avoidance of death is reflected in medical texts as well as in a health care system that often advocates aggressive treatment through training (see below), malpractice fears, and at least until recently, financial incentives. It has been effectively argued that death has been secularized in America, moving from the realm of religion to medicine, which has “killed” death through avoidance, aggressive treatment and institutionalization.

The American medical attitude towards death may indeed reflect that of the larger society. Michael Ignatieff commented on this when he wrote:

Cultures that live by the values of self-realization and self-mastery are not especially good at dying, at submitting to those experiences where freedom ends and biological fate begins. Why should they be? Their strong side is Promethean ambition: the defiance and transcendence of fate, material and social limit. Their weak side is submitting to the inevitable¹³.

This avoidance may be the reason it is so difficult to find reliable data capturing American attitudes towards death¹⁴. Riley reports that most Americans “often” think

about death and the majority of people sampled state that thinking about death does not bother them (indeed, one study found that talking about death is often a relief for people)¹⁵. The same study, with a sample of nearly 1,500 participants, found that while 53% thought that “Death always comes too soon” and 14% agreed with the statement that “To die is to suffer”, a vast majority thought that “Death is sometimes a blessing” and that death is tragic for the survivors, not for those who die (89% and 82% respectively). Riley’s study also found evidence that greater education and higher economic class are associated with more optimistic views of death.

Almost seventy percent of Americans prefer to make their own decisions about their medical care (as opposed to the doctor making the decisions). One small study that tried to identify issues of importance to people near the end of life found the presence of family, physical expressions of caring, a desire for truth and control in decision making to be factors that matter most¹⁶. Other factors mentioned included a discussion of practical issues (e.g. finances), an opportunity for life review, social presentability and spirituality. Another study found that older people have less anxiety about death if they live in familiar surroundings or with relatives¹⁷. These and other indications of the need for social support emphasize the paradox in our society that tends to isolate dying people¹⁵.

Race, ethnicity and culture also play a role in attitudes towards death. In many non-white families (especially immigrant Asian and Mexican families), for example, patient autonomy is less important than the ability of the patient’s family to make the final decisions³. However, as Koenig points out, efforts to use racial or ethnic background as simplistic, straightforward predictor of beliefs or behavior “will lead to harmful

stereotyping of patients and culturally insensitive care for the dying.”¹⁸ Culture is only a meaningful predictor when taken into account in the context of a patient’s unique history, family constellation and socioeconomic background.

The Place of Hospice

When cure of an illness is no longer possible and the inevitability of death is accepted, a kind of care other than the medicalizing hospital or isolating long-term care facility must ensue. This care must focus on addressing the physical, psychosocial, psychological and spiritual needs of individuals at the end of life when the burdens of “curative” medical therapies outweigh their benefits. Responding to this call, the modern hospice movement began in 1967 when a woman named Cicely Saunders began St. Christopher’s Hospice in London. As hospice caught on in the United States in the 1970s and 1980s, economic and social pressures aimed at finding cheaper and more humane ways of dying gradually increased its popularity. A major boost was given to the movement when Congress authorized Medicare reimbursement for Hospice services in the mid 1980’s in an attempt to lower medical costs. Although some of the results have been mixed, hospice care satisfaction has remained at least comparable to conventional care, with generally lower costs⁴. More definitive studies, however, are needed to quantify the economic ramifications of hospice care on our health care system.

More Americans are choosing hospice today than ever before. In 1995, about 17 percent of all people who died were served by hospice (400,000 in total). Aside from the rare residential hospice facilities, hospice is generally not a physical space, but rather a

way of caring for people that integrates the principles listed above. Indeed, most patients receiving hospice care live at home and are encouraged to stay there as long as they feel is comfortable, often until death. Staying in the home provides for many practical freedoms and can vastly improve comfort for many patients. Aside from the practical concerns hospice also affords patients a sense of control and ability to be with their family that allows for significantly more psychological support.

In order to qualify for hospice reimbursement, beneficiaries must have a life expectancy of six months or less. The median length of survival once a patient enters hospice care is about 60 days³. The majority of hospice patients are admitted to the program with a diagnosis of cancer, followed in frequency by diseases of the circulatory system (mostly heart disease)¹⁹⁻²¹, while the fastest growing group of hospice-care recipients are AIDS patients.

About a third of hospice patients are admitted to hospice with inadequate pain control. However, once enrolled in hospice, fear of inadequate pain control is not a significant consideration amongst patients receiving care²², possibly because hospice is so proactive in discussing and addressing issues of pain control with patients. In some cases (up to 20 percent) denial of death amongst the patient or family (or both) is detectable on admission and at times persists until death itself. Once people enter hospice they tend to stay in it, as most discharges from hospice care occur due to the patient's death (90%). The vast majority of hospice service providers are nurses, home health aides, and social service providers. There are ten times as many nurses and three times as many volunteers working in hospice as physicians, yet hospice personnel are more likely to receive

medications and physicians' services than home-health patients are²³.

An overwhelming majority of hospice patients are white (80%), reflecting admission bias and several utilization barriers such as lack of volunteers from non-white communities, lack of awareness and referral amongst non-white practitioners and little outreach to communities of color²⁴. Different cultural attitudes towards death and dying and economic class may also play a part in the choice of setting for the dying process. Studies also show increased levels of care afforded white patients once they enter hospice in comparison to their non-white counterparts. Lack of geographical access to hospice is another barrier the movement must struggle to overcome in the coming years²⁴.

In his 1993 study, Thorpe identified eight conditions necessary for increasing the number of dying patients that could be cared for in the home within a given community. These include adequate nursing care, a night care service, good symptom control, confident and committed general practitioners, access to specialist palliative care, effective coordination of care, financial support and terminal care education²⁵. Hospice integrates these elements in an interdisciplinary approach that patients are usually satisfied with. Indeed, the word palliative, hospice's fundamental principle, is derived from the Latin *palliare*, which means to disguise or cloak. Paradoxically, hospice provides care that can uncloak meaning in the dying process for many individuals.

Saunders' initial emphasis remains much of what guides hospice today: effective symptom (especially pain) control, the use of volunteers, care of the patient and family as a unit, care that includes the patient's home setting, and follow-up care with the patient's family after death. Hospice rests on the assumption that since death is a natural event it

need not be hastened or postponed. Rather, hospice offers palliative care that enhances comfort and improves the patient's quality of life. Indeed, hospices have been instrumental in developing new methods of pain relief and management that have infiltrated conventional care settings. Communication with the patient and patient autonomy as the decision-maker in issues relating to his or her death is also a paramount goal of hospice helped by the fact that patients usually stay at home to die. Hospices use nurses, chaplains and social workers to make the majority of home visits. Physicians are involved mainly as consultants. Despite an increasing trend towards privatization, voluntary nonprofit groups still own most hospices.

Hospice is also of tremendous help to the family of the dying individual. However, while the majority of patients who utilize hospice services are deeply thankful, they do recognize some of its limitations. Joining hospice often means a severing of the connection to the referring physician (see the section on physician struggles). In addition the flood of personnel entering the home may contribute to a loss of privacy and at times a feeling that the family is no longer in control. At the same time, the patient's relatives often benefit not only from the help offered while the patient is dying but also from the grief support and counseling offered after the death.

Many barriers to the use of hospice remain. The prediction of the terminal diagnosis is a difficult task, with errors usually falling on the side of over-estimating life expectancy^{11, 12}. This is a problem in hospice care as the services offered are usually of benefit only if provided for more than just a few hours or days. Clearly, a more objective set of prognostic criteria is needed in order to convince patients of the practical value of

hospice in various stages of their illness²⁶. Issues of aggressiveness in treating infections or exacerbation of illness in dying patients also come into play in hospice as many older sick people on the verge of death often exhibit signs of these. The focus of hospice remains on treating symptoms rather than finding a cure⁴.

Additional roadblocks to the use of hospice come from Medicare limitations on in-hospital days and low reimbursement rates, which lead hospices to require patients to have 24-hour caregivers before they are admitted to a program. Lack of physician education on hospice referral and palliative care remains another obstacle to patient referral to hospice services. Indeed, one study suggests that at least one fourth of those who have the opportunity to discuss hospice with a terminally ill patient never do so²⁷. The difficulty of accepting that a diagnosis is terminal and communicating that fact to the patient and the harshness of terminating an ongoing relationship may lead to under-referral from home healthcare nurses and doctors^{28, 29}. Also, the reluctance of home care agencies to refer patients to hospice remains an obstacle in an increasingly competitive field where patient volume means profits. In addition, family denial and ambivalence about the abandonment of curative therapies make the decision to enter hospice increasingly complex, as more high-tech service in the home becomes available³⁰. Finally, Janice, one of the hospice nurses in the current study pointed out that “hospice” (like “morphine”) is a loaded word in many cases. “Hospice to the patient, [and the] patient's family buys into this too. Hospice means death, you know, and it means that there's no hope. And it means that you're giving up on me, Dr. so and so.” Thus, the barrier to hospice use can at times stem from the simple fear of death.

The Training of Physicians to Work with Dying People

There is much in the training of physicians that counters the palliative model of care. Physicians are taught to solve problems, attack disease and interrupt patients in order to get the “necessary information”. There is little emphasis placed in most medical textbooks or school curricula about communicating bad news, listening compassionately or providing care for the entire family. While almost all medical students recognize the importance of discussing end-of-life issues with patients, few feel prepared to actually do so and over 80% favor more education on these issues³¹. Although the past twenty years have seen a significant increase in medical school courses on death, many of these remain in the realm of electives, with many medical students still graduating unprepared for the realities of dealing with dying people. Physicians who had been taught concepts concerning terminally-ill patients and their families while in medical school report a more “positive” attitude towards death than those who received no instruction³². Other studies have identified more favorable, less fearful and less avoiding attitudes with respect to death and dying as a result of death education³³⁻³⁷.

A pioneer in communication, during the late 1960s Dr. Elisabeth Kübler-Ross broke the taboo of speaking directly to patients about their feelings³⁸. She reported that most patients found relief in speaking openly about death and dying, thereby ushering in a new era in communications between doctors and patients. Following her publications of this and other research, the past two decades have seen an increase in residency education in palliative care in parallel to the growth of the hospice movement. Yet almost thirty

years after Kübler-Ross made her observations, research indicates that in primary-care residency programs interns and residents often care for only 10 terminally ill patients per year, and only a third of the programs include a hospice rotation³⁹. Other studies point out that in self-reported assessment, 37 percent of residents feel inadequate in telling patients they are dying, 29 percent don't feel sufficiently competent in talking to the family after the patient has died and 22 percent feel inadequate at obtaining a DNR (Do Not Resuscitate) order⁴⁰. Strauss points out that while technical aspects of terminal care are planned, reported and reviewed by superiors or colleagues, psychological and social aspects of terminal care are carried out on the basis of private individual initiative and judgement and are rarely part of accountable decision-making⁴¹. Curricular development on these issue is currently quite active⁴², but patients today are still likely to encounter physicians who are inexperienced or uncomfortable with speaking directly and honestly about death and dying.

Where This Thesis Fits In

As the hospice movement grows and death slowly emerges into the spotlight of academic discussion, there is a renewed interest in research on death and dying in the 1990s, particularly fueled by the Robert Wood Johnson Foundation research funding into these issues. Death and dying are again becoming popular topics of study, a change that seems to be motivated by both the aging of the general population and the economic changes in the health care of dying people, paralleled by the growth of the hospice movement.

Within the diverse setting of death outlined above, my thesis focuses on those cases where ill individuals engage with health-care practitioners as they near the end of life. The project is comprehensive of neither all contexts of death nor all possible relationships between practitioners and patients. It does not aim to describe the dying process in its biology, clinical course or psychology. While it touches on issues of ethics and decision-making, the project does not serve as a direct or thorough discussion of advanced-directives, physician-assisted suicide or euthanasia. The primary goal of this paper is to explore the practitioner-patient relationship in search of the subtleties and lessons – practical, psychological and spiritual - of what can be learned for future work in such settings. The goal of this research was education and awareness, both for me and for the reader.

Chapter I - The Research Question and Methods

*You never know what life means till
you die:
Even throughout life, 'tis death that
makes life live,
Gives it whatever the significance.*

The Ring and the Book
Robert Browning, 1868-69

The Research Question

In choosing my research topic, I knew I wanted to experience the presence of dying people. With an undergraduate background in religious studies, I have long understood that death is a supreme teacher about what is important in life. As a future physician, I knew I would be exposed to disease and death and wanted to prepare myself to process these realities in a constructive way. As Ram Dass says, “part of our agenda as people of any age is to find some way of being with the idea of death.” With the guidance of my committee members, I arrived at the central issue of exploring the relationship between dying patients and physicians. I decided to approach my project from a qualitative perspective, primarily through one-on-one interviews with health care professionals and dying people.

Although I did not start out with a preset hypothesis, my purposes were several: First, I wanted to learn more about the reality of death and dying from a patient’s perspective, particularly the interaction dying patients had with physicians. What were some experiences they liked? Experiences they did not? What were dying individuals expecting from physicians? How does the dying process make dying patients different

from other patients? Second, I wanted to learn about the struggles and benefits physicians encounter when working with dying people. How do physicians approach patients with terminal diagnosis? What emotional responses do physicians go through? What is hard about working with dying people? Finally, I wanted to collect the different perspectives in a way that allows the reader to consider the viewpoints of the patient and physician simultaneously. In considering where this thesis will probably end up – on the shelf of the Joint Medical Program – I considered the target audience to be primarily future physicians – hence the recommendations collected in the conclusion are aimed at practitioners who choose to work with dying people.

The Data Collection and Description of Subjects

The data collection for the thesis consisted of fourteen audio-taped one-hour interviews with health-care providers and dying patients. I came into the interviews with a list of prepared questions (see Appendix A), which I used as a rough outline and a template for making sure the interview was somewhat complete (if time allowed). I took as my guide Muller's assertion that "the fundamental principle of qualitative interviewing is to provide a framework within which participants can express their own understanding and experiences in their terms."⁴³ Hence, I did not rigidly seek completeness or order in my interviews, rather preferring a natural flow for the conversation. The interviews were transcribed by three professional transcribers, with one of them responsible for the majority of the interviews (10 out of the 14) and myself.

As death is inevitable, all of us are technically dying. For the purposes of this

thesis, however, I defined “dying individual” as someone who has been given a diagnosis of having six months or less to live by a health care practitioner. I recruited subjects through word of mouth, calling physicians, hospices and other organizations supporting dying people and asking for referrals. While it was fairly easy to find health-care practitioners willing to be interviewed, it was exceedingly difficult to find people who were dying, hence making random sampling impossible⁴⁴. Quite simply, many of them are busy doing other things, and had no time, strength or willingness to speak to me, a stranger who had nothing to offer them in return. In addition, recruitment by word of mouth led to further selection bias (see below). Practitioners had to be physicians, nurses or chaplains who have worked with at least ten dying people within the past two years. Nurses and chaplains were also screened to ensure contact with ten different physicians who were caring for dying people within the past two years. Although my emphasis among the caretakers was on the physicians, I chose to include non-physician practitioners in my study, assuming that they may have valuable perspective both as practitioners working with dying people and as third-party observers of the physician-patient relationship.

Potential subjects were first screened over the telephone to verify their willingness to participate. The protocol I used for recruitment and interviewing was approved by U.C. Berkeley's *Committee for the Protection of Human Subjects* and assigned code 98-1-85. It is included as Appendix C.

The interviews were conducted in February through April of 1998 and all lasted between forty-five to eighty minutes. Interviews were conducted in English at the

patient's or practitioner's home or office, in a private room, and at a time convenient to the participant. One interview with a nurse practitioner was conducted at a café at her request. For the interviews conducted with dying people, family members were always present in the room and occasionally contributed to the conversation. This was not intentional, but in all of the cases family members gravitated towards the room where the conversation was taking place and I chose not ask them to leave (I felt as if that would alienate the dying patient while I also valued the perspective of the family members). It is difficult to say how the presence of family members may have biased the responses of the dying patients.

Interview subjects fell into the following demographic categories:

- Three dying patients, three nurses, two chaplains, six physicians.
- Seven women and seven men. Each gender was represented in each subject category.
- Physicians:
 - Three were oncologists (Carol, Gabriel and Paul), two were internists (Mary and Max), one was a family practice doctor (David).
 - Three were hospice medical directors (Carol, Paul and Max).
- Nurses:
 - Two were hospice nurses (Janice and Wayne), one was a hospital-based nurse practitioner (Heather).
- Chaplains:
 - One was a hospice chaplain (Roberto), while the other was a hospital-based

chaplain (Maya).

- Patients:

- Two in their seventies, both dying of cancer (Laura and George), and one in her forties dying of cystic fibrosis (Ariela).
- One of the cancer patients (George) is receiving hospice care, while the two other are not.

In referring to particular interview subjects throughout the paper, I have changed the names for confidentiality and will be using first names only. Where appropriate, I described the subject's status (e.g., patient, hospice nurse, hospital physician, etc) for clarity.

Sources of Bias

There were several sources of bias in my study. First, the selection of subjects leaned towards hospice-based physicians and their patients because I recruited through word of mouth and the hospice community is a place that actively engages issues of death and dying. Views of practitioners working in hospital or community settings and those of their patients may be underrepresented, although hospice does include these categories to some extent. As hospice is usually expensive, patient participants tended to be more financially stable or to have adequate health insurance. Participants were overwhelmingly white (all but one physician who was Asian), involved in allopathic medical care, and English speaking. Understandably, my selection criteria favored those patients and physicians who were willing to talk about issues of death and dying, very likely skewing

the results. Most importantly, the predominance of practitioners over dying patients (11 to 3) skewed the perspective heavily. Unfortunately, patients' voices are often missing or neglected on many of the issues I explored, despite the richness of the data. In selecting the quotations, I almost always presented them as they were spoken, i.e. with the errors in grammar and incomplete sentences naturally occurring in the dialogue. In a few instances I deleted repetitive information from the text of the quotation. I did not attempt to select equal number of citations from all categories or to proportion the number of quotations to the number of individuals in each category.

The type of interview I chose also biased the findings. I selected Patton's "Interview guide approach"⁴⁵, where topics and issues to be covered are specified in advance in outline form, leaving the exact sequence and wording of the questions to be decided during the interview. While this method had many advantages, it also allowed for important salient topics to be inadvertently omitted. The differences in sequencing and wording of questions may have reduced the comparability of responses. The largely non-dichotomous question style had several pre-suppositions, but also may have helped bring out responses by showing the interviewee that I was not judgmental of certain viewpoints. For example, by asking, "in what way would you like your physician to improve?" I made the assumption that patients wanted their physicians to improve (which was not always the case), but I also allowed patients the safety that, as far as I was concerned, it was natural or even expected for them to be critical of their physician.

Finally, as an interviewer, my personal bias was difficult to ascertain. Being relatively young and with no history of major illness I have not been close to death in my

personal life. I have never witnessed the death of a family member, having lived in a different country than my two deceased grandparents when they passed away. Having a family background of distrust in allopathic medicine, I tend to identify with skepticism about physician's approaches to treatment. When thinking of death I expect it to be a somewhat transformative experience, and tend to romanticize the dying process. As a medical student, I fear situations in which I would have no time to connect with my patients. Finally, as a medical student, my bias is that of a perspective physician – my approach to the interviews was aimed at becoming a better physician in the future.

Organization of the Remaining Chapters

The remainder of this paper is organized around bringing out the salient points from my interview transcripts. It is interview-driven, taking a grounded approach towards the data⁴⁶, and does not aim at a complete analysis of physician-patient relations in the dying phase. My approach in writing is at presenting the issues as they arise in the developing relationship between the practitioner and the dying person. Chapter II focuses on how practitioners and patients deal with what is chronologically the first part of the dying process for many patients – the terminal diagnosis and ensuing choices about treatment. Chapter III concentrates primarily on the patient's perspective on the relationship with physicians and other practitioners, focusing on what patients want from doctors. Chapter IV relates perspectives on the practitioner's relationship with the family. I devote chapter V to comment on fears, conflicts and benefits physicians' experience when working with dying people. In each of these chapters (II – V) I try to integrate the

perspectives of both practitioners and patients with appropriate insight from the literature on death and dying. I conclude with a look at where death in America is heading, a list of recommendations aimed at physicians working with dying people, and suggestions for further related research.

Chapter II - Diagnosis and Prognosis Related Issues

What tormented Ivan Illych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result.

The Death of Ivan Illych
Leo Tolstoy, 1886⁴⁷

Perhaps even more fundamental than the transition from health to disease is the transition from illness to the terminal state. Though it is clear to most individuals that life inevitably ends in death, the knowledge that one is ill and tangibly closer to that eventuality often changes many attitudes and relationships for the dying person and the health-care provider. In this section I seek to spell out some of the particular reactions of patients and practitioners to the initial terminal diagnoses, changing prognoses and death itself.

The Terminal Diagnosis

Arriving at a terminal diagnosis is difficult for many physicians. Death is often equated with failure in medical training. Practitioners may themselves be uncomfortable thinking about death or afraid of the patient's reaction to the bad news. In addition, practitioners often have the belief that giving a terminal diagnosis will take away hope for either patients or themselves. Consequently, practitioners can at times participate in denial about the terminal reality of an illness. This is often manifested by avoidance of the topic altogether. Ariela, a patient who is dying with cystic fibrosis, described her doctor's avoidance simply when she said: "...my doctor, he's very compassionate. And we talked

about death at different occasions, you know, me always seeming to bring it up.”

Once they arrive at a terminal diagnosis, studies suggest that most physicians in the United States share that diagnosis with their patients⁴⁸. Professional and social ethics as well as personal wishes of the patient and family seem to play a strong role in this decision, as does the age of the physician. Physicians younger than age fifty are likely to have fuller disclosure of the terminal diagnosis than older physicians are³². This finding is compatible with two national studies that found that in 1961 only 10 percent of physicians offered full terminal prognosis disclosure to their patients⁴⁹, while by the 1980’s this had become a widespread tendency⁴⁸. Several practitioners raised the issue of past conflict between themselves and family members who wanted the terminal diagnosis to be kept from the dying patient. For these doctors, the autonomy of the individual tends to take precedence over the will of the family unit on this issue, as long as the patient’s mental status is stable.

The consequences of not sharing the diagnosis are significant to both the patient and the practitioner. One physician noted that “if they [patients] think that you’re not telling them everything, I’ve found people’s imaginations much worse than the truth most of the time.” Another observed that “patients usually know already anyway.” Nevertheless, having the conversation with the patient can be very difficult and is often delayed by practitioners. Wayne, a hospice nurse, noticed how this difficulty could adversely affect hospice care through late referral by physicians – a very common problem for hospice patients:

You know, it’s really difficult for a physician...who has been trained that the meaning of the Hippocratic Oath to them is that if they cannot

cure their patient, they have failed. And to sit down and to talk to a patient about the fact that the chemotherapy, the radiation, the cardiac meds, whatever you have done your very, very best to help them has not worked is really hard for them to do.... And so you wait. And you wait until things crash, until the patient or probably the patient's family call and say, 'Things are out of hand. The pain's out of control. I can't get my mom out of bed.' You know? Whatever. And then they call on hospice as a last ditch effort

Wayne's observation stems from the fact that it is often a scary and sad task for physicians to tell their patients about a terminal diagnosis. The act requires the physician to distance himself from the viewpoint of the patient because, as one physician put it, "if I let myself put myself in that patient's position and stay there, I wouldn't be very therapeutic because I would be a puddle of tears."

If the underlying fatal disease is not chronic, patients often react with shock when given a terminal prognosis. The word "cancer" in particular has layers of cultural and emotional associations that may trigger a crisis when heard for the first time⁵⁰. A similar reaction can take place when an uncertain prognosis turns into a terminal one. Physicians experienced at giving such diagnoses often learn to expect the shock, and tailor the encounter with the patient in such a way as to allow the patient the space to react. Remembering that any information discussed past that point might well be forgotten, some physicians write down important information or save it for a later contact with the patient. Others repeat the information again at a subsequent session. Laura, a patient with cancer, tells of an interaction with her physician that was not so open. Here, the oncologist delivering the news was quick to move into a discussion of outcomes, probabilities and treatment options. The discussion was wasted on Laura, who was quite distressed:

And he's trying to explain things to me that's concerning math, where you have to think, you know? And here he's just told me that I

probably only have so much time to live. Well, I can't think about these circles that he's drawing and everything else over here. My mind is still on what he just told me, that I don't have very long to live, you know, and I can't get past that...he just said, "You're not very good in math, are you?" And I said, "No," you know? So he just - he had no understanding of what I was going through at that moment at all. He probably says it so many times a day, but for me it was devastating, to say the least. You know? That's all I could think about--what I had to accomplish, you know, and how much I had to get done before that time comes.

One reason that Laura's physician was so quick to move on to a discussion of the epidemiology of her disease and treatment may have been his own personal discomfort with a terminal diagnosis, or his own feeling that death is a failure. Almost every practitioner and patient I interviewed alluded to this as one of the most common problems of physicians who are working with dying people. As doctors are trained, paid and entrusted to help cure diseases, they are often taught to see death as a result of a medical mistake or shortcoming⁵¹. The inability to recognize death as a natural, inevitable process leads to over-treatment of symptoms and a medicalization of dying that is often irreversible. Death is so often seen as a failure within the biomedical paradigm, that articles on the "naturalness" of death become significant in the debate of end-of-life issues, reminding physicians of this basic fact⁵. The numerous psychological defenses afforded by the position of denial, as well as the ability of modern medicine to control the tempo and form of dying through technology, have contributed to the rampant forgetfulness amongst physicians that death is indeed inevitable.

A second reason that may explain the behavior exhibited by Laura's physician is the fact that he may have been anticipating in his mind the next question that patients often ask - "how long do I have?" Most physicians are extremely uncomfortable answering this

question, as they have all either seen or heard countless counter-examples or unexpected outcomes. A common theme in many of my interviews was how unpredictable disease was, especially cancer. Some people seem real weak and fragile yet last a long time, while others tend to look strong and healthy and suddenly just die. One doctor only gives his diagnosis in terms of “many days, many weeks, many months or many years.” Others don’t even venture a guess.

After the Diagnosis – Abandonment and Reassurance

After the terminal diagnosis is made and communicated to the patient, it is not unusual for the doctor to refer the patient to another physician or care organization – usually a specialist or hospice. In this case the physician is essentially abandoning the old relationship with the patient. The reasons for this abandonment are many, from fear or feelings of incompetence or helplessness by the physician to practical concerns about cost and time. The end result, however, is that in many cases a primary relationship and means of support for patients is lost just when it is most needed. Ariela, a patient with cystic fibrosis, has had a prolonged terminal phase to her illness and has dealt with many physicians throughout this time. When physicians feel there is nothing more they can do, she says, “they kind of get that look of pity in their eyes.”

In the hospital setting, abandonment turns to avoidance. Mary, a hospital physician, describes the process as it affects her and fellow physicians:

I’ve seen people grow impatient after making the diagnosis. People stop coming by the room, don’t go in and sit and talk, feeling like they failed the patient, feeling guilty for not having saved his life. I feel that way sometimes too. It kind of creeps in unconsciously. You start to notice, before you were spending half an hour with this patient. Now

it's down to 5 minutes.

Research of patient conditions in several large hospital wards supports Mary's observations as indication of a systemic problem. Lost in their "fight against death", physicians often neglect intervention to maintain patients basic comfort: "oral hygiene is often poor, thirst remains unquenched, and little assistance is given to encourage eating...distancing and isolation of patients by most medical and nursing staff is evident; this isolation increases as death approached."⁵² Discomfort with the reality of death concurrent with a futile battle against it often leads to a worse death for the patient both physically and psychologically. Indeed, true-to-life medical practice rarely adheres to the AMA's patient's "Bill of Rights" for end of life care, which promises dignity, trust and communication⁵³. When the patient is abandoned, she feels more and more removed from human contact. Often reeling from a terminal diagnosis already, isolation can lead to neediness in a patient, a quality that often turns practitioners away and leads to further isolation for the patient.

The alternative to abandonment or avoidance by physicians is patient education and reassurance. George, one of the patients I interviewed, who suffers from cancer, spoke of his relief when the physician reassured him that "you will know everything we will know." He was also comforted when his physician assured him that he would stand by him throughout the illness. This set the stage for even greater disappointment when his physician was constantly busy and interrupted during appointments. George felt so undervalued he stopped visiting physicians altogether.

When physicians do not abandon patients they often display other defense

mechanisms that help them deal with dying patients. One common reaction is for physicians to place the burden of death onto the patient. Ariela talked of her physician telling her that she had control over when she will die:

You know, at one point [my doctor] said to me, "You will die when you no longer have a desire to live." [laughs] OK. And I think that's what he was talking about more, was that, you know, that drive to survive and that, you know, wanting to be a part of life, and I think that's what he meant. Now, I can be somewhat spiritual, but I'm also a little cynical. And part of me thinks that, you know, no matter how strong your spirit might be, if your body is weak - weak, weak, weak, weakening - you know, then it doesn't matter.

This approach by a physician, whether consciously undertaken or not, is double-pronged. It carries within it the possibility of empowering the patient and possibly giving them a sense of greater control over their destiny. On the other hand, many patients' situations deteriorate even when they really want to live. At that stage, placing the responsibility for life and death onto the patient runs the risk of demoralizing her and alienating her from the physician. In truth, the physician needs to realize that he has no idea when the patient will actually die.

Even for the dedicated physician who does not abandon, avoid or place responsibility of death on the patient, the relationship with the dying patient is complicated. Particularly when discussing death and dying issues, physicians must be in tune with patients' needs and desires. Some patients seek a listening ear and counsel, while many do not. The physicians I interviewed all had an appreciation for patients who remain in denial and for whom denial or avoidance is preferred. George was one such patient. In his words, "I already know the facts, I don't need to be reminded of them." George's attitude may remain as it is until his death, or be a part of a continuum of

reactions terminal patients may go through. McCormick and Conley describe a patient's perspective on this continuum as she made the distinction between feeling "incurable" versus "terminal":

Being incurable meant that I would have to live with it. I knew that I was going to die, but I regarded that as something in the future. I didn't know when that would happen, I was more concerned with living as much as I could, getting as much done with the amount of illness and discomfort that I had. Incurable meant that I had to face dying, but I could face it in the same sense that everyone does. We're all incurable, everybody dies, and I'm going to die just like everybody else. Terminal meant that I had less time. It meant that dying was now and countable. It is now time to prepare myself to die⁵⁴.

Physicians who are sensitive to changing attitudes and continue to check in with patients are more likely to respond in an appropriate and timely fashion.

Approaching Treatment

The views of death as failure manifests not only in the reluctance to arrive at and speak of terminal diagnoses, but also extends to the approach practitioners take towards treatment. While many doctors leave the choice of treatments up to the patient and his family, several practitioners spoke of physicians who continue to treat aggressively past the point where it is obvious that treatment is futile, causing needless suffering. A change in this attitude is essential for the provision of better palliative and spiritual care. As Callahan puts it, a more productive approach would view death as "that to which medical care should be oriented from the outset in the case of all serious, potentially life-threatening illnesses, or of a serious decline of mental and physical capacities as a result of age or disease."⁵¹ Patients often will not share this non-interventionist attitude, however.

It is worth noting that about half of the physicians surveyed report acting against their own conscience in providing care that they see as overly burdensome when the patient or their family want “everything possible” to be done⁵⁵. That death is the enemy is still a social belief, not merely a medical one.

Seeing death as the enemy also blinds practitioners to the other aspects of a patient’s life. Ariela, the patient with cystic fibrosis, related an anecdote that illustrates this point vividly. One of the doctors that was treating her was trying to convince her to have a lung transplant, probably assuming that because she was dying her quality of life was unacceptable:

And the doctor says to me “Well, have you thought about a transplant?” And that’s what they say to all the patients at end stage. It’s like “Well, come on! You don’t want to die, do you?”... So we had this discussion. He said “well, the one thing people who get transplants say is that at least they finally have a good quality of life now.” And I looked at him and I said “I have a good quality of life now. I don’t want a transplant and I’m fine.”

Ariela’s story is an example of aggressive treatment by a physician who views dying as a medical failure. Alternately, physicians may simply be in denial about the prognosis and approach treatment as successfully curative even when no such medical precedent exists. George, a patient who was dying of cancer, told a story of surgeons telling him “we cured you” even though his type of cancer had never been successfully cured by Western medicine. Such a reaction by a physician may arise out of both a fear of death and a rescue fantasy. Unrealistically optimistic prognoses often lead to frustration and distrust among patients, as they irresponsibly play on the hope and faith the patient is struggling to preserve.

Both physicians and patients can approach treatment in different ways depending on their attitude towards death. When specific communication and alliance building around this issue does not take place, the potential for distance and separation between practitioners and their patients is great. An important key to proper management of illness lies in adequate communication between patient and doctor, with the physician willing to relinquish control to the patient and her family. The next section aims to elucidate some facets of both the patient's and the physician's struggle for control throughout the dying process.

The Struggle for Control throughout the Dying Process

The dying process involves a myriad of changes in a patient's life. The body begins to deteriorate, with resulting symptoms such as fatigue, loss of bladder or bowel function, depression and pain. Both illness and medications take a physical and often emotional toll, or have side effects that directly influence a patient's mental state. Daily schedules change as visits to physicians and other caretakers increase, taking time out of other activities. Various treatments, both towards healing and towards palliation must constantly be considered, adhered to or rejected. The role of the patient within the family unit may change, as well as her self-image. As these changes occur, many individuals experience a loss of a sense of control over their lives. Whether it is the inability to control their bodily functions, strength or level of pain, the ability to predict events and processes in life is often greatly diminished, and a resultant dependence on others grows. Disease, treatment and deterioration take on a pace and life of their own. Carol, an

oncologist who works primarily with cancer patients, explains her view of the situation faced by many of her patients: "Boy, do people feel out of control with this diagnosis, and, you know, they not only are told what chemotherapy they should get, but the schedule. You have to come in and stay at this time and, you know, all of a sudden their life is controlled by a schedule and a doctor's office."

Often, the suffering associated with loss of control is great. With it can come a loss of one's independence and initiative, spontaneity and uniqueness, indeed the very sense of self that permeates our psyche is often tied to our sense of self-determination. As a result, the struggle in the dying process is often tied to the struggle to achieve, maintain or slow down the loss of autonomy. The struggle to stay alive becomes the daily battle to maintain these aspects of personality in the face of disease.

As control over the circumstances of one's life diminishes, the fear of losing control becomes greater, sometimes overwhelming. It is this issue that often brings out the most intense struggles for patients. Janet, an experienced hospice nurse discussed the lack of a sense of control as the major factor in the few patients she has worked with in her career who have expressed suicide ideation. When these patients regain their sense of control, they often stop feeling suicidal:

...they feel they're not going to be able to bear the pain, to control the pain, or they're afraid of the dying process. You know, it's the fear and the anxiety, or their sense of abandonment and loss that's causing them to think about shortening their life. It's that loss of control... When they find out that they can control their pain, that they will have people that promise to and will be there so that they don't have a sense of abandonment, and that they will have control over their treatment, and over their treatment choices, and over their life until the very last, and will be able to die with dignity, and that we will help protect that for them, then all of a sudden that goes away.

So in a sense, the process of both dying and of caring for the dying can be looked at from the viewpoint of balancing the tasks of helping patients maintain a sense of control while simultaneously taking care of the dying body and changing physical and emotional needs. Issues of power and paternalism are often brought out in the personal interplay around these changes, no matter whether the caregiver is a family member or a professional.

The issue of control is multifaceted. The caretakers of the dying person may experience themselves in a situation of conflict – of caring for someone while simultaneously contributing to their loss of independence. This is often better than the alternative – isolation, abandonment and physical suffering. From a spiritual viewpoint, however, the suffering associated with a loss of control can sometimes lead to transformation, and the loss of predictability of life before death may be useful in bringing out fears and uncertainty about death or what comes after death. Thus, a loss of control may in some circumstances be helpful to dying persons, especially if such anxieties are a significant part of their dying experience. Max, an internist and hospice medical director brings this point out as he discusses the difference between caring for dying people versus caring for people who are non-mortally sick:

When you're dealing with a person who's just sick but still in control, then you're just helping them to get their life back in order and get everything put back together. And that's a different process than someone who's dying, where the outcome is generally pretty mysterious and totally uncertain and often terrifying. It's a different - the loss of control is kind of instrumental to people making their way through that process, where you don't want to facilitate people losing control when they're sick. You want to get them better. And that's maybe the difference that physicians don't often appreciate, that the loss of control is an integral part of the dying process, and it's to be appreciated and worked with rather than recoiling from it in horror, like most of us physicians do, because we're very control oriented.

As the last part of Max's quote brings out, a caregiver must also be sensitive to his personal reaction to the dying person's struggle. The physician must continue to ask such questions as: is the loss of control so debilitating that the struggle to regain control becomes primary? Is the patient using the loss of control to explore other issues as death approaches? How does this change over time? What is the patient asking for – more control or more guidance?

The practitioner must be able to contend with the patient's struggle for control without feeling threatened herself. The effort to maintain control is often fundamentally linked to the patient's need to survive. One of the persons I contacted in the course of this project put it succinctly when he said "most dying people are not busy dying and wouldn't call themselves 'dying', they are busy living!" This means that patients often maintain a high degree of control throughout their struggle to heal or gain closure. When the patient and the physician's agendas do not match, the patient's struggle for control may lead to abandonment by a physician. Laura, a patient who has lived with a rare form of cancer for the past seven years, experienced such a conflict with her own physician as she sought alternative treatments for her disease. Her oncologist did not approve of these alternatives and was upset every time she brought up one of them as a viable treatment option. Subsequently Laura felt abandoned and alone:

He would just poo poo those things, you know, and ignore them, like, you know, "That's a waste of time. That's a waste of money," and all this kind of stuff. Well, and that would make me upset because he wasn't doing anything, I felt, to further my treatment, you know? And so I was having to do it all. And he was very cold to me... Maybe he doesn't like the idea of me going on my own. I know a lot of people, they just go to the doctor, and the doctor tells them this and that, and they go, "Yes, sir," or whatever, and they don't ask any questions, and they don't say how they feel or anything else. Well, I'm not like that.

And [laughs] that's probably maybe hard to take for some of them, you know? Because if they say, "Well, I want," you know, "this should be done or that," I'm the one that says, "Why?"

It is difficult to speculate on the cause for her physician's attitude: ignorance, a feeling that further or alternative treatment is futile or risky, or perhaps another reason. Regardless, what this physician failed to recognize was this patient's struggle to survive and need for control. The physician was unable to relinquish the lead in the care of this patient.

Allowing the uniqueness of each death to take shape may be scary for physicians. Two of the nurses interviewed saw the fear of losing control as a major barrier for physicians making house calls on dying patients. From their perspective, physicians fear of losing their authority and professional relationship away from the clinic environment. Indeed, to enter the patient's home is to make oneself vulnerable – to be willing to live with an uncertainty of how you will be treated, with knowing that you can't just leave the room, of opening up to judgement from family and friends. Perhaps most importantly, it reveals a non-sanitized view of death and exposes the physician to a fuller realm of suffering - one that is often avoidable in the office visit. Visiting the home is scary and involves a certain amount of risk. On an interesting note, it was mentioned as one of the most beneficial experiences by those patients who received home visits as well as those practitioners who do them.

In contrast to Laura's experience, another patient told a very different story. Her doctor was willing to give up control and was able to let Ariela, the patient, "be in the driver's seat" while simultaneously being available for support when and where she requested it. She is thankful for this attitude in her physician:

I mean he's been my doctor for thirteen years and knows me pretty

well, and, you know, I think he's kind of amused by me in different ways, but respects me a lot, respects my assertiveness and my desire to pretty much call the shots in a lot of ways around my care, and has been more than accommodating to me that way; doesn't have a big ego.

Indeed, from the patient's perspective, a doctor's ego is yet another obstacle to overcome in the struggle to achieve control through the dying process. To be effective in giving support to the dying patient, a physician must be willing to relinquish control.

In addition to allowing the patient to take an active part in the medical decision-making, some physicians and hospices make an effort to offer their patient active support in the form of meditation workshops, support groups and relaxation techniques aimed at directly addressing the issue of control. A simple but often-ignored question physicians must learn to ask their dying patients is "How do you feel about your sense of control over your life? Your care? Your symptoms? Your treatment?"

When asking these questions practitioners must also be willing to hear the answers. To do so a practitioner must give up her idea of what death *should* be like and open up to the reality of what death *is* like, which can vary from patient to patient. It is useful to develop emotional equanimity in the face of those deaths that involve calmness, opening and communication as well as those that include anger, denial, sadness and frustration. To be attached to one sort of death – to try to get patients to a certain place in their dying - is likely to invite a sense of failure and frustration. Death, by its nature, is out of control and unpredictable. It seems that practitioners must learn to embrace these qualities if they are to survive emotionally and spiritually in the midst of dying.

Chapter III - What Dying Patients Want From Their Physicians

When in doubt tell the truth.

Mark Twain

Like people who suffer from illness, dying individuals have a wide range of expectations from their physicians. To the extent that physicians fulfill her expectations, the dying person will allow herself to be supported and cared for by her doctor. While in no way comprehensive, the interviews brought up some common gaps between what dying patients want and need and the care they receive from physicians. In the previous section I already discussed the patient's struggle and need for control in the context of coming to terms with the terminal diagnosis and treatment. An examination of other patient preferences and lacks can allow for insight into the experience of many dying patients with their medical care, while giving practitioners a necessary perspective as they care for dying people.

Time, Attention and Communication

The lack of frequent, honest communication with physicians was a theme that came up in all of the interviews I had with patients. The patients wanted to know everything the doctors knew but not to be misled by speculation or false optimism. Interestingly, all three patients mentioned checking the Internet for medical fact and opinion as a sort of a check on their physicians. But most importantly, patients often complained about physicians' lack of time, caring or listening skills. Janice, a hospice nurse, brought this out in her perspective as an observer to the relationship between the

doctor and patient:

I very rarely hear a complaint about a physician giving me the wrong medicine, not doing something to make me better. What I hear complaints about is that they don't listen to me. That they don't ask me, you know, how I feel and what's going on with me. That they don't seem to have any time. You know, about never getting to see them. That they're real brusque on the telephone. It's all social.

Janice's comment brings out a fact that physicians continue to struggle with, particularly in the age of managed care – the diminishing time resources they are able to devote to their patients. Interestingly, all of the physicians I talked to also mentioned this as a source of dissatisfaction in their practice. At a period of life when time is so precious, there is simply no substitute for patients if their physician is unable or unwilling to spend time with them. George, one of the patients with cancer, stopped seeing his physician and hadn't seen a doctor for three months by the time I interviewed him. "He got so many telephone interruptions it was like a train station in there," he said, describing his appointments. His decision to stop seeing his physician was confounded by the realization that the doctor had nothing left to offer him as he entered the last months of life. One wonders whether a doctor who is too busy to listen indeed has much to offer the dying patient. Elisabeth Kübler Ross noted that being busy isn't always coincidental when she wrote that "patient isolation is an indicator of our tremendous discomfort in facing the fact of our own finiteness and our wish to avoid it, depersonalize it, or deny it."⁵⁶

Maya, a hospital chaplain, commented that patients seem to be angrier when doctors don't have the time to be with them, because they expect more from physicians. She commented that "...there's a way in which the doctor probably represents God more than I do as a chaplain because [patients] equate, I think, more saving possibilities to the

doctor.” Indeed, patient expectations from physicians may at times make the unavailability of physicians a more bitter pill to swallow.ⁱ

While George willingly left his physician, the attitude and setup of a busy doctor helped drive him away. In many cases patients want to maintain a relationship with a physician where they know the doctor is still interested in them and hasn't withdrawn simply because they are dying. Several chaplains and nurses talked of patients who felt abandoned by their primary physician to oncologists or hospice care. This impression can contribute to a sense of loss and isolation at a time when these feelings already predominate. In general, dying patients want physicians who will stand by them even when there is nothing more they can do from a medical perspective. The appreciation patients felt about physicians who do take the time to make house calls and visit dying patients at home underscored this.

Reassurance and Spiritual Care

In addition to competent medical care, many dying patients seek information from practitioners about what will happen as their disease progresses and how well their symptoms will be controlled. That this need by patients is not fully appreciated by doctors was underscored by one study that found that in 65% of the cases, physicians underestimated their patient's desire for information⁵⁷. Many patients simply want an experienced hand to tell them the possibilities of what they can expect. Some desire simple assurance that they will not be abandoned and that the appropriate referrals will be

ⁱ Interestingly, studies confirm peoples' greater comfort with clergy than with doctors, though doctors far outrank lawyers and insurance agents.¹⁵

made³⁹. Other patients are particularly concerned about pain or the side effects of medications aimed at controlling pain, and want reassurance that they will be able to die with dignity or with a certain level of consciousness. Interestingly, when a patient is assured that he will get sufficient pain medication, some evidence suggests that the need for pain medication actually decreases⁵⁸.

A physician is often the ideal person to answer questions and provide reassurance, as her knowledge and experience often elicits a degree of trust that is not matched by other practitioners. However, doctors may often not be the best resources on some of these issues, as they are not the ones putting in hours by the bedside or actually caring for dying patients on a day to day basis. In many cases patients learn to depend on nurses for information as much as on physicians. Indeed, research indicates that patients prefer physicians who are open to accepting input from other health care practitioners such as nurses and clergy³⁹.

In what may come as a predictable finding by now, many patients have learned not to expect spiritual support from their physicians. Maya observed a sentiment that was echoed in my interviews with patients when she said: "I think they are open to that, but probably don't expect that. Doctors are too busy. I think when it happens, they're thrilled." The sentiment illustrates a reality that is in many ways reflective of modern medicine and its self-fulfilling prophecy. By emphasizing the mechanical aspects of the body, doctors have largely become technicians, losing the healing role that many patients prefer but have learned to stop expecting. Roberto summed this up with an observation about the doctors that he has encountered in his years of hospice work:

[Physicians] are very much into their cool, rational, diagnostic mode,

which is very good in terms of getting at information about what's the cause of the problem with the illness... But most of them are not very capable of relating to the patient as a whole person rather than to focusing on what the illness is, the diagnosis. Again, that's a generalization, and there are doctors who just blow that right out of the water because they're not that way at all.

Interestingly, while most practitioners agreed with Roberto's assessment, a few of the physicians I interviewed did not. Those physicians who disagreed conceive that most patients do indeed expect psychological and spiritual care and support from physicians. This gap in perceived patient expectations between physicians and other caretakers may simply be a product of sampling differences and selection bias, but it may also reflect a real difference between physician self-concept and the reality going on around them. This testimony affirms that often physicians are not the empathic, understanding and caring guides and helpers they and their patients want them to be.

Ariela, the patient with cystic fibrosis, had this simple advice for doctors who want to better care for dying people: "Listen. Instead of telling. Listen and - not just listen, but obey. When the patient says something and even recommends something, you know, to really consider that maybe that would be worth doing, instead of having your own agenda." Indeed, having a specific agenda of how a patient should die or what a "good death" is and projecting that onto the patient can be a major turnoff for patients. Two of the patients I interviewed felt slightly imposed upon by what they felt to be the religious dogma of their physiciansⁱⁱ. Patients found spiritual support much more effective when it involved appreciation and space around their individual dying process.

ⁱⁱ Interestingly and perhaps ironically, physicians who define themselves to be religious also seem to report a more positive attitude towards death in some studies.³²

Warmth and Physical Touch

In addition to time, attention and reassurance, many patients mentioned warmth and a generosity in physical touch as qualities they want in their physician. Dying people are often feared and ostracized by other members of society, at times even by their own families. As a result, many feel isolated and alone. People, including physicians, are often afraid to speak with individuals who are dying, or they worry about upsetting them or speaking about difficult or inappropriate topics. As a result, dying people often thirst for companionship and intimacy as they near the end of life. Laura, a patient who has been dying of cancer for the past seven years and was in the terminal phase of her disease at the time of our interview, was able to articulate her needs clearly:

So that's what I need right now. I need somebody that I can feel I can depend on and that I can talk to if I need to. I want to feel like my physician - and if you go into this field, you know - that you're a part of the patient's treatment. I mean a part of their life really in helping them to make decisions and maybe if, you know, maybe a little hug once in a while [laughs], you know, or a pat on the shoulder, or just something, you know, that you care about them, you know, instead of being so cold.

The issue of physical touch can be even more overwhelming to dying patients. At a time that they are most dependent on others to take care of their bodies, they often encounter a reluctance or fear of human contact. Thus, daily interactions can contribute to a feeling of devaluation for dying patients, creating a great thirst for physical touch. All of the patients I interviewed talked about wanting others, especially friends and physicians, to touch them more. Simple tasks like hugging carry added meaning at this time of life. George, a patient with a three-year history of cancer, tells a tragic story from his own past about his

mother that was probably triggered by his own feeling of neglect, as is evident at the end of the quote:

When my mother passed away, it was really funny...the doctor came in to sign the death certificate, and he was afraid to touch her. And I thought "a doctor?" It was like, this poor doctor was totally wiggled out over the fact that someone had passed away. And it was hard for me to imagine, you know, how do you ever get through medical school if you have this emotional hang-up. It was amazing to me. But, yeah, he didn't want to touch her and it was just, "hey," you know, "she's not going to bite you." She died of congestive heart failure, nothing contagious. Yeah, be that way... You know, I haven't gotten a hug since I got my diagnosis.

The lack of touch manifests particularly when it comes in a context where touch is expected. Laura, one of the patients with cancer, talked about how short her physical exams have gotten since her physician decided that her diagnosis was terminal. She expressed this concern not in the context of worry about medical completeness but rather in the context of her physician being cold and uncaring. By the time Laura found a physician who was warm and always gave her a hug or a pat on the shoulder, she was so relieved that she "didn't care if he wanted to cut my legs off." Understanding the importance of physical touch may help many physicians give their patients the attention they deserve, and can be a moment of grace and connection.

Chapter IV - Family Related Issues

University Hospital, Boston

*The trees on the hospital lawn
Are lush and thriving. They too
Are getting the best of care,
Like you and the anonymous many,
in the clean rooms high above this city,
where day and night the doctors keep
arriving, where intricate machines
chart with cool devotion
the murmur of the blood,
the slow patching-up of bone,
the despair of the mind*

*When I come to visit and we walk out
into the light of a summer day,
we sit under the trees –
buckeyes, and sycamore and one
black walnut brooding
high over a hedge of lilacs
as old as the red-brick building
behind them, the original
hospital built before the Civil War.
We sit on the lawn together, holding hands
while you tell me: you are better ...
I look into your eyes*

*which are sometimes green and sometimes gray,
and sometimes full of humor, but often not,
and tell myself, you are better,
because my life without you would be
a place of parched and broken trees.
Later, walking the corridors down the street,
I turn and step inside an empty room.
Yesterday someone was here with a gasping face.
Now the bed is made all new,
the machines have been rolled away. The silence
continues, deep and neutral,
as I stand here, loving you.*

Mary Oliver

Families play an integral part in the care of the dying patient. In the hospital, members spend time with the patient and often serve as his/her advocate with house staff. In the home and even at the acute care setting, families carry much of the load for the physical and emotional and financial care that the dying person receives^{59, 60}. Family members wash, clean, move, cook, feed, drive and clothe many patients in their final months, weeks and days. In addition, people close to the patient carry much of the load of dealing with the psychological and spiritual aspects of the dying process. Physicians working with dying individuals, whether they choose to or not, often interact with the entire family. Dying people are rarely treated in isolation – they come in with their family, the discussions and home visits are with the family, phone conversations include the family, as well as treatment decisions. To fully appreciate the patient-physician dynamic we must therefore examine the relationship between physicians and the dying patient's family.

Who is the Family?

It is important to remember that families vary as much as patients do. Patients may have many relatives nearby or alternately be more lonely and isolated. David, a primary care doctor who works with many AIDS patients as they die, notes that the family may not always be genetically related to the dying individual: "I think - again, there's that flexibility, realizing that family of origin may have little importance, and it may be their family of friends, lovers, whomever may be, that they're all part of it. And so you really

have to pay some attention to them all.” Several of the practitioners I interviewed also mentioned patients who had no family to support them, in which case the practitioners, mostly doctors and nurses, became the patient’s family. In these circumstances more time was spent with the patient talking and affirming her decisions and listening to the process of life review.

Stuck in the Middle – the Practitioner’s Place in the Midst of Conflict

One theme that came up several times in my project was that of practitioners finding themselves caught in a conflict between the patient and the family. As the practitioner usually identifies with the dying person as her primary patient, she often finds herself in a position of having to protect the patient from actions by the family that she deems unnecessary or harmful. Loved ones have their own emotional process around an upcoming death, and may experience responses that resemble those of the patient or the physician – acceptance, anger or denial to name a few. Paul, an oncologist, was particularly impressed by repeated experiences of family members trying to do everything they could to hold on to their loved one. He often perceived the behavior of family members as abusive clinging to the patient:

I've had families shove food down someone who wasn't hungry because they want them to eat to keep going. Just back off. If he doesn't want to eat, he doesn't want to eat. I says, “Don't nag. Encourage him, but don't nag him.” You know? Same thing with pain or anything.

Paul’s reaction is not atypical for practitioners who feel protective of their patients.

However, there are several risks inherent in intervention such as his. First, a practitioner can easily project her own preferences about a good death onto the patient. Second, the

practitioner may often lack insight into the subtleties and history of family dynamics.

Perhaps “nagging” is not just holding on but rather a way of expressing love in a particular family relationship. Perhaps the patient wants to be nagged. Interference and advocacy without initial communication with the patient or family run the risk of alienating both parties.

The decision of whether to interfere in the dynamics between the patient and the family can at times be difficult and not inconsequential. Mary, a hospital physician, talks about being forced into such conflicts and having to play the role of patient advocate with a family where fear of the dying process is strong:

Sometimes it is hard if patient has made it very clear to me that they want to die at home, for instance, that it is frightening to them to think of being in a hospital or being alone then that puts me in a middle of a disagreement sometimes with the family, because the family may feel that they can't tolerate that. It is too frightening for them to have a patient being there at home dying... I find myself in that situation trying to advocate, because I feel that I know really well what the patient wants. Sometimes I try to help the patient to convince their family of what's possible and desirable at the end of their life.

In addition to clinging and fear, family members may experience the upcoming loss as a last chance to resolve conflict with the dying person. When the dying person is not willing to engage the family on that level, conflict may ensue, inducing feelings of protectiveness in a practitioner. Roberto, a hospice chaplain, speaks of such an event involving one of his hospice client and his daughter. Like Paul, Roberto felt a need to protect his patient from what he perceived to be emotional abuse:

I sometimes find that the patient is fine and the patient is ready to die and the patient is - but the family is really making it much more difficult for them, and I get impatient with them. And I said once to one daughter of a patient, "Your father's dying. When you come into this house, don't bring old baggage with you and make it harder for him."

That blunt with the daughter, because she was doing that. The guy's dying, and she wants to resurrect some old grievances she has, and it's fine to kinda resolve the conflicts, but it's not fine to try to hammer them down and, in effect, get revenge for what's happened, which was what she was doing. She was battering him emotionally. She wasn't going to try to, you know, resolve the unresolved conflicts; she was just trying to get even. Which he doesn't need. Now, if he needed to deal with that, but he wasn't up to it.

From an outsider's perspective, it is difficult to judge whether Roberto's intervention was useful. The examination of these conflicts between patient and family makes clear, however, that to be an effective advocate for the patient one must be willing to engage the family in meaningful communication about their response to the dying process. A conversation about how they feel and what they expect the dying process to involve is necessary to understand the full context of the patient's emotional life. Moreover, a practitioner must examine his own emotional response to family interference and take care to not act simply out of that response. A good way to make that assessment seems to be simply through asking the patient about their family relationships.

Practitioners as Bridge-Builders

Another theme that evolved out of my conversations with practitioners is that often the relationship with the family can be aimed at bridging a gap between patients and their loved ones. The difficulty of talking about dying is a strong barrier in many families. Often both family and dying patient want to speak of the topic but are afraid of creating discomfort or upsetting the other. To the extent that this big "elephant in the living room" is on everyone's mind and interferes with the expression of thoughts and feelings, this can lead to a sense of isolation and separation for both patient and family. Another

unfortunate outcome is that such silence can interfere with important healing work that can happen around the time of death. As many practitioners pointed out, silence often leads to a feeling of “if only” soon after the death, whereas communication can potentially lead to a place of acceptance and forgiveness, and can be transforming for all parties involved. Health-care practitioners can help relieve this discomfort by modeling talk about dying, and by inviting others to participate if they choose. As one practitioner put it, “it doesn’t mean the pain goes away, but at least we’re sharing the pain instead of feeling isolated and suffering.”

By simply acting as a third party, a practitioner can directly participate in the communication between a dying patient and a family. The combination of authority and support in the physician’s role can help bridge some of the most difficult topics. Carol, an oncologist, tells the story of how one of her patients with breast cancer used the doctor’s office as a setting to safely communicate with her husband and daughter, despite her husband’s denial:

And, you know, there have been some very intense, very moving experiences I’ve had where the patient and their family will use the doctor’s office as a forum - I’m sort of a third party who can facilitate - and a safe place to talk, whereas home might not be. So I’ve had people come in with their - a woman came in with her husband and daughter, and that’s where she said, “Tell me, you know, how long do I have to live, and what’s it going to be like to die?” because then her family could hear that from me, and everyone could react with me sitting there. And it was a very - a very moving time because the husband was, of course, having a very tough time seeing his wife dying, and he was crying, and he didn’t want to hear any of this, but she did, and he was listening to it for her, and, you know, the balance between being realistic and not losing hope. And so our office sometimes is a forum for that. If it doesn’t happen here, it can happen at home with hospice present. Some families are able to do it without any third party there at all, and other families never do it.

To enable a dialogue between a dying patient and her family a practitioner must remember that he is not just an advocate for the patient but also for the family. Being present to listen and hear the concerns of family members at this moment is a great gift one can give to a family and patient dealing with death.

Taking on the Family as a Patient

The theme of giving direct support to families came up in several of the interviews. It was particularly strong among those practitioners and patients involved in hospice which views family support as one of its fundamental principles. Supporting families can take many forms, one of the most important of which is telling them what to expect in a timely manner. Family members often depend on such predictions in making decisions and balancing their own responsibilities as they care for a dying loved one⁶¹.

Another important way practitioners can help families is through giving permission. Permission to be angry or upset, permission to let go of dying patients and permission to grieve are just a few examples of the support and reassurance that practitioners can give the family. Such permission supports loved ones to be emotionally present at a time when so much more is required of them. Family members have to deal not only with the approaching death of a patient and but also with the heavy consequences of each of their decisions: "Should I wake him? Should I feed him? Am I giving too much painkiller?" Also on their minds are practical matters concerning the rest of their life after the death such as "who's going to pay the rent when he dies?" At times they are so involved in caring for the dying person that they neglect their own health. Indeed,

research shows that family members caring for dying people suffer increased rates of anxiety, depression and chronic illness and a general decline in physical and mental health⁶²⁻⁶⁵. In those situations, it becomes the job of the practitioner to recognize them as the “hidden patients”, remind them of their own needs and, if appropriate, to care for them as well. In the hospice setting, this support often continues after the death of a family member in the form of bereavement support groups.

At times, a family member’s cry for help is disguised in aggressive or confusing behavior, especially in the setting of acute illness or hospitalization. The astute practitioner knows not to react to aggression by family members, but rather tries to explore its roots. Mary, one of the hospital physicians, talks about such experiences:

Many times the way the people show that they feel guilty, say about their mother, is they are very mean to the medical staff, they are very demanding, or they are complaining all the time. I don’t mean that those can’t all be justified complaints, but the way it is done, makes me know that the person is feeling like they need to do more. Sometimes it takes the form of people not showing, not coming. Sometimes it takes the form of them blaming the patient in some way. So the first thing is to recognize, to get clues, that’s how the family members feeling. The second step to help them say it. And it may not be explicit. And it may not be comfortable to actually say: “I feel guilty that I didn’t see my mother more before she was here in the hospital.” But often times people can acknowledge that in general sense they feel there are things that are incomplete. And then another thing is just to say something like “a lot of people feel that way” to emphasize to them the good things that they did. “A lot of people and their families would not have done what you did in terms of staying with them these last few days, that has meant a lot that you are here now.”

Mary’s experience echoes that of many of the other practitioners I interviewed. From the practitioner’s point of view, the fundamental key to supporting family members is to really listen to them, to take in their perspective and to hear their difficulties and wishes. The

practitioner must view herself as their partner in caring for the dying patient and in helping them make the appropriate decisions about care. Supporting the family at times of emergency or acute crisis in particular not only allows them to make the most appropriate decisions consistent with the patient's desires, but also helps the physician get an understanding of who the patient is and thus come to decisions consistent with the patient's wishes.

Mary's situation also points to the many places where practitioners may be judgmental of families. Every practitioner has an idea of the sort of family support they would consider to be "good", and when families don't measure up to such expectations judgement may arise. One physician plainly said "I get mad at their families sometimes, because I feel they are being chicken and not coming through to the patients." The feeling of the finality of death may further exacerbate the practitioner's judgment, as well as the family's judgement of practitioners. The general feeling that no second chances exist intensifies anger, defensiveness and guilt in all parties involved. The sense that death is a unique time for resolution and support may also increase frustration with a patient's difficult family situation. Several practitioners who work closely with substance-abusing patients expressed sadness over the fact that many of their patients are distant from their family and quite lonely – a state that leads to more emotional separation. One doctor lamented a case where parents that had been apart for many years came back together for a daughter's death only to ignite old fights and arguments that in his view took away from the sacredness of the dying process. Training, practice and a commitment to advocate for the patient and his family are needed to help practitioners see beyond their own

judgements in such cases

Informing a family about what to expect as the patient nears death is an important element in the communication between the health-care practitioner and the patient's loved ones. The stress of the dying process is further accentuated by our society's lack of familiarity with it. Indeed, at times physicians themselves are unfamiliar with the possible progression of functional loss, emotional stages and pain as the patient progresses towards the end of life. Yet as practitioners we have an obligation to learn and educate our patients. The questions the family wants answered are often quite simple but they may be difficult to answer. Heather, a hospital nurse, talks about the difficulty of having patients ask about prognosis:

Heather: ...I've had a lot of people say, "Am I dying?", or patients, family members say, "Are they dying?" They want to know. And it's a really hard question.

Interviewer: What's hard about it?

Heather: I mean they're asking to play God or Goddess. But I think if people ask the question, they want, they're ready to hear the answer. And you can never be sure...But it's hard when people really come out and say, "You know, what do you think? Are they going to make it through the night?" And having to look at people and say, "You know, I don't know. They may not. They may not, you know, be here tomorrow." And what I would do is encourage family members to sort of go in and say whatever they wanted to say or stay with somebody as long as they wanted to, or to reassure them, no matter what happened, that the person would be kept as comfortable and pain free as possible. And I think some people - it's not so much the fear of death, but they fear that the person's going to be in pain

As difficult as such questions about prognosis can be, the answers, even if uncertain, often provide tremendous relief to the families of dying people. During several of my interviews, patients expressed gratitude to physicians and hospice workers for "telling us what to expect." Conversely, one of the more distressing events was a lack of warning

where patients felt some could have been given.

Support for the families need not stop with the death of a patient. Research suggests that families are at increased risk of morbidity and mortality in the grief period after a death⁶⁶. Grief counseling in hospice or attending funerals are some of the more practical aspects practitioners can engage in, as well as informing the family that certain symptoms they are likely to experience (e.g., depression) are normal. Another aspect that can really support families is reflecting back to them the appreciation that was felt by the patient. Telling them that they were loved and appreciated by the patient, using specifics, can offer a reassurance that many family members can use at a vulnerable time after a death. Heather, a hospital nurse, described such an experience during the death of her own grandfather:

I remember waiting in the other room, and the nurse who came in to tell us that he had died, I mean she was just amazing. You know, I introduced myself and, you know, she had worked with my grandfather for about a week then. And my brother was there and my sister. She knew all our names. You know, I had never met this woman in my life. You know? And she said, "Oh, you're Heather. Oh, right, you're the oldest," you know? "And this must be Christopher." And she's going, "Your grandfather talked so much about you." You know, and she knew about our lives, and she knew what she did from spending the time with my grandfather. And, you know, I think it was just the way she did it. I mean really it meant so much to me as being on the other end, that, you know, that she spent that much time with him, that she knew about us. I mean there was just a willingness on her part to be there with us in our grief... You know, the doctor walked in afterwards, and he was like "Oh, you know, your grandfather was old, and he had diabetes" I mean he was like apologetic. But, you know, it just didn't compare.

Heather's story points to both the need many practitioners feel to comfort the family and how simple effective comfort can be. The intellectual, removed synopsis in this case is far

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inferior to sharing of yourself and of your own relationship with the patient. Such sharing often gives the family the reassurance that the patient was cared for with attention in the last hours and days.

For practitioners, comforting families after a death is a part of accepting families themselves as patients in their care for dying people. This acceptance is fundamental to effective communication with the family. Moreover, it requires a real commitment in terms of time and effort from a practitioner. Family members come with questions and at times even make their own appointments. The effective practitioner must be prepared for these possibilities or be able to refer to someone who is – namely hospice.

A final fact to remember about working with families is that their needs may be quite different than those of the patient. Personalities and ways of coping may differ as well. One of the cancer patients I interviewed, George, was quite uncomfortable speaking directly about death and his worsening prognosis. However, his wife was quite eager to hear every detail of what to expect and the medical details. They were happy with their primary physician because he was able to accommodate them both through separate appointments, and opened the door to both of them in his communications. This understanding was a key to his success as a physician working with a dying person.

Chapter V - Struggles and Benefits for Practitioners

*Life is short, the art long, timing is exact, experience
treacherous, judgement difficult.*

Hippocrates

In parallel to the struggles of patients and their families during the last weeks of life, the work with dying people brings up many fears, struggles and conflicts in health care practitioners. Those that work with the dying directly tend to be a self-selecting group, yet this does not mean that the work becomes easy. Death and dying elicit some of the deeper and more intense reactions in many individuals, encompassing fears, judgement, compassion and understanding. Almost universally, the practitioners I interviewed saw this work as an opportunity that has added meaning to their life. As one practitioner put it simply, “this work keeps you honest.” In this section, I will examine the struggles practitioners may encounter in caring for dying people.

Fear of Discussing Difficult Topics

Many of us have discomfort talking about death. It is difficult to predict how a dying person might react to speaking about death and dying. Will they be put-off? Do they want to talk about it? Are they scared or in denial? Will they be looking for comfort I can't give? Do they have a spiritual or religious notion of it that is in conflict with my own? Lots of uncertainties make such a discussion difficult. Fear of being confronted with our own issues surrounding death is inherent in every decision we make as far as bringing up the topic. David, one of the family practitioners I interviewed, points out that practitioners often project their own reticence onto the patient:

I think the biggest thing is, is just the fear around bringing up topics. Doctors are just sort of worried about, well, how are they [patients] going to respond to talking about dying or talking about suicide or talking about whatever it happens to be. But I think the real barriers that doctors don't want to open up are their own, whether it's going to be painful or you're really sad to have to talk about that. I mean if the person desperately does not want to talk about it, that person will let you know... And it's better to hear it from them than to make your own guesses around it because, you know, it gets too complicated with your own stuff

To truly communicate with dying people as they near death a practitioner must be willing to examine his own “stuff” around loss and the end of life. In this way the practitioner can increase awareness of his own barriers to engaging with dying patients. Like working with a population that is at risk for STD's and where sexual practices must be discussed, a practitioner interested in providing spiritual care to patients must have the courage to discuss a delicate topic without falling into the trap of trying to fix. Unlike STD's, death is neither preventable nor fixable, hence practitioners have less to “do” and have to learn to simply listen in a non-judgmental way. Mary, a hospital-based internist, reiterated this point when she said “...how comfortable the patient feels about discussion has almost entirely to do with how comfortable we feel. People will talk about sex, death, religion, everything else quite comfortably if we are comfortable asking the questions.”

Fundamentally, those working with dying people have to actively engage their fear of death as a process. The practitioner must have a certain degree of acceptance of human mortality to be an open resource to dying people. As one nurse put it, “you can't be afraid to catch death from dying people, or you just won't go in the room.” To care for the dying, one doesn't have to conquer death or the fear of death, but rather be willing to engage it. On the physical level, this means physicians must not be afraid of touching

dying people, as is all too often the case (all three of the patients I interviewed pointed to this as a problem in physicians). In addition, individuals must be willing to deal with issues that go beyond the intellectual level and delve into the realm of feelings. Roberto, the hospice chaplain, observes that physicians often intellectualize in the same way that he does as a chaplain: "...doctors do the same thing: get information, and forget to tune into where the feelings are." To be effective with a dying person, physicians must be able to engage the individual on an emotional level, allow their own feelings to come up, and find a way to process them without dumping them onto the patient or abandoning her.

Fear of Being Unable to Help or Making the Wrong Choices

One common difficulty for health-care practitioners is when they are faced with a situation where there is nothing they can do to help the patient. Though experience tells us that there is much we can do to help individuals as they near death, occasionally there are still patients who remain in misery. For practitioners trained and paid to "fix" things, such a scenario can be scary. From a psychological perspective, the stakes are higher as death approaches – there may not be a second chance to get it right. Janice, a hospice nurse with over fifteen years of experience, talks about her fear of finding herself unable to help a patient:

I think that as a hospice nurse if - and when I'm on call, if I get a call in the middle of the night, the fear that I have is - and I have considerable knowledge in my repertoire - that no matter what I try, nothing's gonna work. And I think physicians have that fear. You know?

Such a fear gains strength after experiences of futility in controlling the pain of others.

Several practitioners mentioned such cases where they were unable to control the pain

symptoms of patients despite high doses of painkiller medication. Indeed a small percentage of all cases of pain can never be adequately controlled⁶⁷, a fact that is central in the debate over physician-assisted suicide.

As with every medical case, fears about making the wrong treatment choice or decision haunt many practitioners working with dying people, and it is not uncommon for practitioners to report taking their work home with them when working with dying people. These doubts can linger not only with issues of not doing enough to help the patient, but also of doing too much. Many practitioners worry about overmedicating their patients and contributing to a premature death. Wayne, another hospice nurse, talked to this issue:

I also think that there is a fear of - that I'm going to actively participate in the patient's death without meaning to. By prescribing the last dose of morphine or, in my case, giving the last - and we don't feel that way anymore - giving the last dose of morphine. And I think it takes a while to get beyond that, you know?

This dilemma is very real for many health-care practitioners today. How was death supposed to happen? Should the patient have had another day – maybe they would have said what they have been waiting to say? Simply put, it is scary to think that you may be killing the patient. Together with a fear of patients becoming addicted to pain control medication, it has historically led to under-medication of pain symptoms in dying patients. Other myths about narcotic medication have also persisted (e.g., unacceptable sedation and mental clouding are common persistent side effects), contributing to confusion on the usage of analgesics⁶⁸. Although physician education and behavior has significantly improved in the past twenty years on this issue, the problem of under-prescription remains

real, with many physicians still afraid to prescribe adequate doses of triplicate-requiring pain medications.ⁱⁱⁱ

Fear of Being Unable to Relieve Pain – Having Nothing to Do

On the flip side of fears about making mistakes in a practical medical sense – the inability to control pain, are fears about killing the patient, etc. These have less to do with a practitioner’s actions and more with her role as a listener. When actions are not what is needed, but rather a listening presence that is open to whatever comes up, practitioners often feel discomfort. Trained to fix, a practitioner may find himself in a novel role at those moments – one of less control and more uncertainty. Mary, a physician, articulated how difficult it can be to just be present for patients when there is nothing you can do:

But if, when it gets down to it, people are just afraid of death, I can’t fix that. I can’t tell them I will make it easier for them. I can’t tell them they are not going to die. And that is very hard for me. And there is nothing to do, and you just have to be there, just sitting there listening and nodding your head, saying ‘I know what you are saying, I can’t fix it, but I am here.’ That is really hard. Have you done that?

That fear – that there will be nothing left to do, can bring up insecurities for the practitioner. Suddenly, he may be called upon to go beyond his training, to take off the white coat, to just be a human interacting with another human. At the same time, it is often unclear if the patient is interested in having the practitioner play that role. Interestingly, my interviews indicated that patients are not necessarily looking to physicians for spiritual support (although physicians often perceive them to be). However,

ⁱⁱⁱ A triplicate requiring pain medication refers to one of the narcotic medications (e.g. morphine) that are thought to have an addictive potential. Their prescription is tracked by the state government using the triplicate prescription forms.

when physicians do offer it, patients are often thrilled to engage physicians on that level.

One of the reasons that patients have learned to not expect physicians to become involved in the spiritual side of dying is that among health-care professionals physicians are perceived to often have the least amount of time. It takes time to listen. Fixing and rescuing are more predictable tasks that physicians are more familiar with. However, as Roberto, the hospice chaplain pointed out, "...rescuing people sometimes isn't what they need. It's much harder to stay with them and help them work through whatever is bothering them." Some practitioners do take the time to do this, while others allow the hospice team or the social worker exclusive domain over this terrain. However, it is clear that the struggle of physicians in working with dying people includes, at least for some, a longing for such a spiritual connection with people. In his essay entitled "The Good Death", Arthur Kleinman notes a scene where a physician has a series of talks with a dying patient over the last several days of the patient's life⁶⁹. In his discussion, Kleinman neglects to mention something that for many practitioners is written between the lines. The death he describes is good not simply because it involves a patient actively engaging his death, but also because it involves a physician taking the time and actively engaging his patient.

Fear of the Feelings that Arise in Dying Patients

Dying patients go through a multitude of feelings as they face disease and near death. Many of these are difficult for practitioners to face. Almost universal amongst the practitioners I interviewed was a discomfort with patients who are angry. Anger can bring

up all sort of emotions in practitioners - defensiveness, guilt and sadness being the most prevalent; and it is often hard to function as a practitioner while having these feelings.

Maya, a hospital chaplain, talks of how angry patients often point out her limits as a practitioner:

Oftentimes people who are dying of cancer tend - and I don't want to say everybody, but there are a number of people who die from cancer who are very, very angry. And, you know, that's just part of where I meet some of my human limitation. It's harder for me to be with people that are angry and raging. And so I'm sure I can't bring as much peace and as much of the fullness of my being because I'm meeting my own human limitation there.

Other practitioners spoke about their struggles with their own response to patients who are angry. Anger in a dying patient often elicits in a practitioner a greater sense of responsibility to react in a way that does not contribute to the isolation of this patient. At the same time, practitioners working with dying people are already stretched out emotionally – dealing with (or suppressing) their own issues that arise around death. Angry patients, therefore, present both a special challenge and a special opportunity for practitioners working in the field of dying.

Another situation that is often difficult for practitioners is seeing patients die alone. Several physicians expressed anger at families who “were chicken” or “didn’t come through for the patient.” For others, the sadness of dying alone was one of the hardest realities, and motivated them to spend more time with dying patients as opposed to their other patients who were not dying. Heather, a hospital nurse, describes such a situation:

Interviewer: Do you treat them [dying people] differently from other people in any way?

Heather: Well, dying can be - like in the hospital dying - I spend a lot more time with my patients who are dying in the hospital, a lot more time, a lot more attention.

Interviewer: Why?

Heather: I guess it's to my own, again, personal spiritual beliefs, especially if it looks like, you know, the family or support friends may not be able to be there as much. I hate to see people die alone. This is my own thing. You don't come into the world alone. I feel it would be hard to go out alone.

Heather's reaction is interesting for its content but also for its subtext. It points to the fact that practitioners are strongly affected by their work with dying people, and must find coping mechanisms that allow them to continue their work. In Heather's particular case, her way of coping with the sadness of the loneliness of certain dying patients is to spend more time with them. Other practitioners may choose therapy, support groups, meditation, writing or other methods. Letting in the emotions and changes in patients runs the risk of overwhelming the practitioner and making them ineffective in their caretaking role. That can be scary. Max, a hospice director and internist, talked about the importance of acknowledging that fear:

I find that the more - the more issues frighten me, the more it indicates that there's something I really have to learn by being involved. And so those are the cases I tend to pick. And, yeah, I frequently am frightened. But I think it's important to acknowledge that. At the same time, it's very hard to be helpful if you're sucked off center into the same terror that the patient and family are in. So you have to be careful to be aware of your fear, but not allow yourself to be sucked off into a place where you can't really be helpful.

Max's point illustrates the possibility of finding personal growth through the difficult aspects of working with dying people.

Fear of not Getting Enough Feedback

Paul, an oncologist and hospice medical director brought up an interesting point

about his frustration with not getting enough feedback through his work with dying people. Not only are there few outcome measures one can point to, but the power dynamics that can arise between a physician and a dying person can make it difficult for patients to give their physician an honest critique. Paul's account is touching in its honesty and frustration:

The hardest part, is you're not - you don't get feedback on how well you did. You can measure how well a fracture has healed, you can measure how well you treated the pneumonia. How do you measure how well you handle a death? You know? And the other thing, of course, is the person that you're taking care of is subject to your whim. Who's going to be critical of somebody that they're dependent on?...I mean I'll tell you a nightmare I have, is that, you know, when I die, I'm going to see all these patients again, and they're going to give me the feedback, you know, of all the things that I could have done better. You know? That's kind of scary. Because I know I'm not perfect. I know I haven't done everything right. Not every one has gone smoothly.

The account also points to the ongoing process of questioning that can arise in those who care for the dying. While the questioning comes from within, the lack of feedback can leave a practitioner in a very lonely place, particularly outside of the hospital setting. The depth of this loneliness is best understood in the context of how important most practitioners find any feedback or support they could get from colleagues. Hospice members grow to depend on team meetings, hospital nurses on shift-change conversations, and physicians on feedback from their staff. Patients, though often more direct as they near death, can leave practitioners with a mixture of not enough feedback or large amounts of direct criticism. Self-judgement and doubt in the face of death are the constant companions for those working with dying people.

Conflicting Sets of Values

Like in the rest of medical practice, work with dying people exposes practitioners to individuals with a wide diversity of values. In many ways, caretakers learn to avoid disagreements and suspend judgement as they work with patients in order to allow for a smooth and friendly interaction. In death as well, the variety of value-systems practitioners encounter mirrors the diversity of the human condition. But beyond normal illness, working with dying does not allow for a glossing-over of value differences between practitioner and patient. This happens for several reasons. Foremost amongst these is that as patients near the end of life they and their family are often more direct and insistent about their preferences. Another is that issues such as pain control, last wishes and religious preferences do not easily lend themselves to brushing under the rug. Many of the practitioners I interviewed pointed to value judgements as a struggle for them in their care of dying people. Maya, a hospital chaplain, talked about her difficulty with patients who she felt had false hope:

I don't do very well with people who have what I feel is a false hope. There's a lot of people that use religion for their denial. And so they really want to deny death, and they don't want to let it in or process it. You know, after six, ten visits and all I hear is "I got faith. It's going to be OK." And they're dying. That's the hardest for me.

Maya felt frustrated because patients with false hope (or in her perception, denial) do not engage their dying process in a way that she feels she can support them. In other situations, practitioners work with dying patients can point them to a better understanding of their own concept of death, pain and disease. This happened to Janice, one of the hospice nurses, as she had a disagreement with a dying woman over the woman's pain-

control regimen:

Every patient is unique. The biggest struggle that I've had as a nurse is the occasional patient that I have that, for one reason or another, has to cling to their pain. In one way or another they sabotage [the pain control regimen], and they don't want to do it. The first time it happened to me, my patient told me: 'As long as I have my pain, I know that my body is fighting the cancer, and I know that I'm alive, and for me I know that that means there's a little hope.' And that for me was a really big lesson.

In Janice's situation, the conflict was one that touched on Janice's own conception of pain and how she herself would like to have pain controlled if she were in the same situation. Through her negotiations with the patient over the pain-control regimen, Janice learned about herself and her own relationship to pain and suffering. She recalled the experience as not only teaching her about the diversity of patients but also as a lesson in who she was – a chance for self-reflection and for acknowledging that which she brings to the table with each of her patients.

Most practitioners pointed to some sort of difference in values with the dying patient for whom they care, but also pointed to the need to serve the patients out of respect to their preferences. This often included respecting denial or silence and not bringing up topics which the patients find difficult. However, as David pointed out at the beginning of this chapter, silence and censorship of topics are only good if explicitly requested- if the patient expressed her preference for it. At the same time, David points out that in his mind, the ideal practitioner is one who is open to the degree that "everything can be on the table for discussion." Silence that comes out of judgement can cripple the relationship between the practitioner and the dying person. Silence that is agreed upon and intentional can be an unspoken conversation of respect and love.

Fear of Losing Patients

The most common struggle for practitioners is that of losing patients to illness and death. It is an inevitable part of working with dying individuals. It brings up sadness and issues of separation, and takes getting used to. Mary, a hospital physician who works closely with patients suffering from AIDS, commented on her difficulty in seeing her patients lose weight. As the patients would get skinnier, Mary compensated by eating:

When I first started doing this, my patients would become skinnier and skinnier, and waste away, becoming walking skeletons, and that would be frightening to both of us. I would get close and then I would fall in. And the way I dealt with it was eating too much, I gained eighty pounds my first three years I took care of people with HIV. And there was a period of time when I realized what I was doing and I stopped getting close to people. And that had it's own problems.

Mary's experience of loss is not atypical for practitioners working with dying people. Learning to deal with the loss requires a difficult balance. With each patient, one has a choice of how close to get – how much to open and identify with the patient. The greater the identification, the harder the loss when the patient dies. In many cases, however the degree of good a practitioner can do for a dying person depends on how close he gets. Conversely, maintaining a distance separates the practitioner from many of the benefits he could receive through working with a dying person – those stemming from the growing presence of truth and authenticity in a person approaching death. Getting close leaves the practitioner liable to get hurt and become debilitated by the loss (one practitioner likened some losses to losing your mother or your father). According to Max, one of the hospice

physicians, the balance lies in not letting a part of you die with each patient.

Losing patients in the midst of a busy schedule can bring up issues of abandonment for patient and physician alike. One physician told of needing to leave a dying patient in order to go to a family reunion, and the associated blame and guilt she has felt from the patient. Most fundamental is the sadness of simply saying goodbye to patients forever – a luxury and a chore for practitioners working with dying people. Heather, a hospital nurse, talked about how draining this process can be:

Saying goodbye is the most difficult part. I find it very draining. And physically, emotionally, spiritually it can be really exhausting to fully be there with somebody during those last days. You're saying goodbye to somebody you cared for deeply. You know? You know you're not going to see them again.

Being human, practitioners are complex psychological beings, whose responses must be considered in the context of the whole person. It is less useful to think of “practitioners who repress” or “practitioners who disengage”. What is more important is to realize that every person is capable of any of these reactions: fear of discussing difficult topics, fear of over-treating or under-treating, and fear over the consequences of difficult choices. Fear of being unable to relieve pain as well as struggle with the emotions that dying individuals express is present in us all. All practitioners search for feedback and grapple with self-doubt. All caretakers have judgements and conflicts with patients over differing values and are sad to lose patients. Yet out of that collage of struggles and fears emerges a more mature and loving practitioner with the capacity to give a tremendous amount to the patient.

Benefits to Practitioners

Practitioners who work with dying people derive numerous benefits from their work. Many of these benefits have been brought up in this section already. In a sense, every struggle carries the benefit of allowing the practitioner to learn more about herself. That the practitioners I interviewed find the work fulfilling is evidenced by their choice to work in the field for many years (although selection bias may be a strong confounding variable here). What is it that practitioners find fulfilling in working with dying people?

The most common answer had to do with the different mind and emotional states that dying people bring to the table. Many practitioners commented on the openness and directness of dying people – of the honesty and closeness of the interactions that makes for intense relationships fairly quickly. Maya, the hospital chaplain, summed these sentiments up as she spoke of her feelings about working with dying people:

There's a Scripture that I think of, and it's like 'take off your shoes, you're walking on holy ground.' And that's what it feels like to me, is there is a - there's a very sacred quality. It's a translucent place where things that are not essential and the bullshit and the facades and the masks and the social pretenses are all cut away. And people relate out of a core that feels very deep and holy to me. So it creates a very deep bonding that in life and in health it may take us many, many years of relationship to get to that point

Maya's sentiments were shared by many practitioners, who spoke of how the work keeps them honest and energized, very rarely depressed. What it comes down to for many practitioners is the ability to get to know patients and their families really well, often crossing barriers of race, class, religion, gender or sexual orientation. The quality of being with dying is often in direct contrast to the busy and unfinished quality many practitioners experience in the rest of their practice.

Several practitioners talked of the simple rewards they find in helping a patient die without pain, or seeing the family involved in the dying process, or knowing that the patient had someone to talk to as they died or that they died with dignity. One hospice nurse spoke of the satisfaction of seeing his patients dying at home – able to smoke a cigarette if they wanted to – unburdened by limitations and moralistic superiority. Although many practitioners spoke of the mystical quality of being present when a patient takes her last breath, rarely did practitioners speak of patients undergoing a transformation as they died. In fact, several mentioned their perception that “patients die the way they lived.” So it was the simplicities of helping someone through a very important time in their life that brought fulfillment to the practitioners. One physician simply stated that working with the dying “...is a privilege. So this is a, you know, it's kind of hokey, but a once in a lifetime deal. And not everybody gets to be involved. So if you're there, I look at it as a kind of an honor.” The trust that a dying person places in a practitioner to allow or want them to be involved in their death is an incredibly empowering burden to many practitioners who work with dying people.

The exposure to the spiritual dimension of people's life is perhaps most direct in practitioners working with the dying. Several practitioners spoke of being exposed to a variety of religious and spiritual traditions and gaining valuable insight and respect for the strength of the human spirit. Practitioners also mentioned how their work with dying people has helped them to develop along their own spiritual path. One doctor spoke of how the spiritual work she did with dying patients prepared her better when it came time to deal with her own breast cancer. Heather, a hospital nurse, spoke of how working with

dying people helps with the basics of remembering her own mortality and prioritizing one's life:

We think if we have the best doctors and a lot of money that death is optional. We forget. But it comes to us all. And I think the gift of working with people who are dying is you get to remember that. And the Buddhists say, "You never know what's going to come first, tomorrow or your next life." I mean it really, it reminds me to stay in touch with my loved ones. You know, what matters. It reminds me to keep my priorities in order.

Other practitioners spoke of how working with dying people helps them learn how to be less judgmental, to be more patient and to get out of the mentality of feeling they have to fix their patients. Working with dying helps many practitioners become more empowering to their patients as they learn about their own inner resources.

Because patients are often more honest as they near death, practitioners treating them are, in turn, called upon to respond in a similar mind-state. This often helps break down many of the barriers that mark the professional relationship in everyday interactions, especially for physicians. Mary, a hospital internist, talked about how she allows herself more freedom to be human when she works with dying people:

Pretty much across the board I'm more likely to talk about anything that comes up. I'm more likely to share my own feelings on experiences. Usually I would edit those out pretty assiduously out of any interaction with a patient. I would never say "I'm feeling depressed today" or "what you said made me angry." I would almost never say those in a normal interaction. Whereas, with someone who is dying, I would more likely put myself in and, as I said before, to follow up on clues about what their feelings are.

Practitioners may often find themselves in a different role with dying patients than they do with their other patients. It is precisely this alternate role – the confidant and the listener and the friend as opposed to the teacher and the advisor and the nag – that

practitioners may find attractive and desirable. In this way, working with dying people can be incredibly rewarding for practitioners. In a sense – the switch from curative to palliative care allows the physician to give up her omnipotence – to become more of a nurse or a midwife than a physician. Many physicians miss this role in their everyday caretaking of patients.

The openness that practitioners often develop as they work with patients may also end up being directed towards the self. Allowing patients to have their emotions as they die also gives physicians contact with their own emotional world. Many practitioners allow themselves to experience acceptance, compassion, joy and grief in new ways when working with dying people. The human connection that the work fosters, both with patients and with one's self, is perhaps the most fulfilling aspect of working with dying people for many practitioners.

Finally, practitioners often directly experience the gratitude of many patients. Dying patients and their families often feel deeply grateful for the support they get as they near the end of life. Laura, a cancer patient, recalled a story of how her relationship with her physician changed when she expressed to him her gratitude:

So he put me in the hospital, and he was very concerned about my white blood count. That was number one. Number two, when he came in to see me at the hospital, he was ready to walk out, and I grabbed his hand, and I held it, and I said, "Thank you," you know, "for putting me in the hospital," because it did make a big difference, and it helped me a lot. And he just kinda looked at me in shock, you know, when I held his hand? So I think maybe he learned something from me. I don't know. You know, that just a touch sometimes can make a big difference in your relationship. But everything changed in our relationship after that. You know? He really seems to care now about me.

Laura's story shows how simple appreciation was an important benefit to this physician.

Such gratitude, along with the other benefits outlined above, helps many practitioners find themselves deeply rewarded and fulfilled as they work with dying people.

Conclusion

*On each branch of the trees in my garden
Hang clusters of fruit, swelling and ripe.
In the end, not one piece will remain.
My mind turns to thoughts of my death.*

-Seventh Dalai Lama⁷⁰

As death slowly emerges from its hiding place in the wards hospitals, we are reminded that exposure to death is important for our society as a whole. The transformation from seeing death as a failure to viewing death as a natural phenomenon and an opportunity for growth, which began with the work of Kübler-Ross in the 1960s, is continuing through the modern venue of hospice. The current debate over the right to die may aid in bringing the discussion of death into the spotlight⁷¹. As hospice helps move death into homes, our fear of, and isolation from the dying process may diminish. Indeed, it has been shown that elderly dying patients who witness a death are in general less depressed and fearful of their own demise⁷². Imagine the consequences if, as was the case at the turn of the century, adults as well as children would see death in the home and reclaim it as a normal part of the life cycle. Reaffirming death can help remove much of the shame often associated with being old. Hospice can help bring this reality to life by allowing us a closer view of death.

Looking Forward

Our society has not yet fully accepted the inevitability of death. If we move towards that direction, we must not fall into the trap of identifying the “good death” and

projecting judgement onto those who do not experience our version of it. Technology has its place, as does fear and anger and pain, for some people. Indeed, to truly accept death we must embrace it with all of its imperfections, as we do with life.

Much work on characterizing death in America and improving hospice care remains to be done and many questions remain unanswered. What do Americans really feel about death? To what extent do dying people even want our physicians involved? How much does it really cost to die in hospice vs. the hospital? Who should pay for death? How can we overcome the problems with under-referral to hospice? How can we change medical education to lead physicians to be more accepting of death? How can we overcome the geographic and racial barriers that make the hospice alternative unavailable to many dying individuals? These are just some of the questions that will drive research and changes in the field in the years to come. Along the lines of this thesis, a worthwhile project would match a patient and her caretaker team to try to more rigorously evaluate their interpretations of the same events and interactions through the dying process.

Recommendations to the Practitioner:

Notwithstanding the inevitable bias and shortcoming of this project, a number of suggestions arise from my analysis of the interviews and survey of the literature. I write these in the imperative voice and aim them at physicians who work (or plan to work) with dying people:

1. Be honest with dying patients. Tell them everything you know without false optimism or resignation. Give them time to take it in. Tell them again. Ask them

what you told them. Watch out for your own denial and defense mechanisms around diagnosis and prognosis.

2. Remember that death is not your fault, not a failure, and not an enemy.
3. Make time for them and talk to them frequently about end-of-life issues – practical, psychological and spiritual. Be warm with patients. Find out the patient's physical boundaries and touch them a lot!
4. Ask dying patients what they expect from you. Ask them what they want to talk about. Ask them how they feel about pain and how they want to approach treatment. Keep checking in with them and being their advocate. Respect the differences among different dying patients. Respect their denial, anger, sadness and loss of control.
5. Don't feel sorry for dying people.
6. Listen to your dying patients.
7. Do not expect anything from death or the dying process. Each death will be different from the others and from your image of what it will be like.
8. Do not abandon dying patients after they get the terminal diagnosis. Keep visiting, going by the room and making appointments. Find out how they feel about your level of involvement. Do home visits!
9. Look at your own feelings that come up through your work with the dying process, especially noticing issues of control. Be honest with yourself about how it affects your response to patients and your ability to care for them. Look at your own fears of death and need to fix things. Look at your agenda for the dying

- patient and be prepared to drop or change it to what the patient wants and needs.
10. Find a source of support for yourself to help process these issues. Talk to your colleagues about your experiences with dying people. Be kind to yourself. Notice when you feel overwhelmed and take some space or ask for help. Be kinder to yourself.
 11. Learn to be okay with doing nothing.
 12. Assess the language used to discuss this patient's illness and disease, including the degree of openness in discussing the diagnosis, prognosis and death itself.
 13. Consider the relevance of religious beliefs, particularly about the meaning of death, the existence of an afterlife, fatalism and hope for recovery and beliefs in miracles. Notice your judgments of the differences between the patients beliefs and your own. Get to know and refer to social workers and chaplains, without abandoning the patient. Listen to nurses, social workers and clergy.
 14. Consider issues of generation or age, gender and power relationships, both within the patient's family and in interactions with the health care team, taking into account the political and historical context, particularly poverty, refugee status, past discrimination and lack of access to care¹⁸.
 15. Establish who the family is and develop timely, frequent and consistent communication geared to their needs. Learn the family's role in the decision-making process and try to understand how the dying process is affecting family dynamics. Be aware of family conflict. Let the family know what to expect and encourage planning. Model talking about death to the family and be the patient's

ally in talking to the family. Accommodate the family's grief both before and after death. Be an advocate for family members and take responsibility for their health as well. Be aware of your own judgement of family members⁷³.

16. Learn about the hospice network in your area and establish firm connections. Tell patients about hospice early and make the referral at the appropriate time, asking for help if you are not sure when it is.
17. Learn a lot about pain-control. Don't be afraid to prescribe pain medications.

Reading these recommendations, many physicians or future physicians may respond with the thought "that would be great, if I only had the time!" Especially in this day of managed care, doctors feel pressed and unable to give to patients as much as they know they want and need to give. Although finding time to be present with patients is often difficult, I believe that those doctors who are able to make the time will be richly rewarded. Being with dying people is a gift and a treasure that doctors are in a unique position to receive. It can be challenging, sustaining and uplifting all at once. It can give meaning to life.

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Appendix A – The Interview Questions

Interview Questions for Dying People:

- Could you describe your illness process to me?
 - How long have you been ill?
 - When were you told that you have less than six months to live?
 - Who has provided you with care since that time?
 - Have you wanted all of these people to be involved in your care?
 - How long have you been under the care of physicians?
 - How would you describe your physician's attitude towards your diagnosis and your illness?
 - In what way has the care you have received from your physician been adequate?
 - In what way has the care you have received from your physician been inadequate?
 - Have you had non-physician practitioners (e/g/ nurses, social workers, chaplains, etc.) involved in your care?
 - Can you compare the care you have received from these different practitioners to the care you received from your physician?
- How well do you think your physician deals with you in real life?
 - What do you think physicians are most afraid of in working with you?
 - In what way would you like your physician to improve?
- What role do you see for your doctor in alleviating physical pain?
 - What role do you see for doctors in helping people die?
- Is there a way that your concept of death influences the care you expect?
- What sort of role do you expect your physician to play in your care?
 - How is that role different from that of the nurse, chaplain or social worker?
- In what way do you think your experience with your doctor(s) is different from that of other dying people?

Interview Questions for Providers:

- Please describe your experience with dying people. How many? What exactly do you do?
- In what ways have you been trained to care for dying people?
- Describe your approach towards giving someone a terminal diagnosis.
 - What do you say?
 - How, if at all, do you mention death specifically?
 - What difficulties have you faced in presenting someone with treatment option?
- Describe your relationship with persons who are dying?
 - In what way do you treat dying people differently from people who are not dying?
- Do you treat people who die from different causes differently? Why?
- Are there things you are afraid to do or talk about when caring for dying persons?
- What has been most difficult for you in caring for dying persons?
- What has been most fulfilling in working with dying persons?
- What do you see as your role in caring for the family of a dying person?

- How well do you deal with dying people?
 - What are some of the things you do well when caring for dying people?
 - What are some things you don't do well?
 - What do you think you are most afraid of in dealing with dying persons?
 - How do you compare to most physicians?
 - What aspects of care do you feel you can improve upon in caring for dying people?
- What role, if any, do you see for yourself/physicians in alleviating physical pain?
 - What role, if any, do you see for yourself/physicians in helping people die?
- Is there a way that your concept of death influences the care you expect/provide?
- What sort of role do (your) dying people expect you to play in their care?
 - How is that role different from that of the nurse, chaplain or social worker?
 - How does this compare to your personal expectation of the role you should play in caring for dying people?
 - How do dying people you work with feel about you/their physician? Why?

Appendix B – Informed Consent and Audio Records Release Forms

Informed consent form for patients:

I am Ori Tzvieli, a medical student at the University of California at Berkeley/University of California San Francisco Joint Medical Program. I am doing research on the care physicians give to patients with terminal diagnoses. I invite you to participate in my research but you are completely free to say no. Refusing to participate will not affect the medical, psychological or spiritual care and support you receive from any individual or organization, because I have no relationship to the services provided by any organizations that may be providing you with care.

If you decide to participate, I will give you a \$20 cash payment to thank you for helping with my research. If you participate, I will interview you for about an hour. I will ask your permission to tape-record the interview. I will ask you questions such as:

“What are some of the physical symptoms you are experiencing right now?” and

“What has your doctor been doing to support you and how do you feel about the care you are receiving? Have you had any expectations that your doctor isn’t living up to?”

If any question is too personal or if you just don’t want to talk about something just let me know and we will move on. Talking about some of these issues may make you feel upset or sad. If you feel upset, please let me know and we will stop the interview. If you experience physical problems or pain during the interview please let me know and we will stop the interview. If you need any medical or mental health services during or after the interview please let me know and I will do my best to help you get these services. If I can do anything during the interview that will help your comfort please let me know.

I will keep all the information I get from you completely confidential by labeling it with a code rather than with your name. I will store the tape and transcript in a locked cabinet, and I will store the code list in another locked cabinet. I am the only one who will have access to the cabinets. I will not use your name or identifying information in any reports of my research. I will not share any of the information you tell me with any of the staff at any facility where you receive care.

There are no benefits to you for participating in this project except the opportunity to talk about your experiences. I cannot provide you with treatment or advice of any sort. However, I hope that this research will benefit patients and doctors in similar situations to yours in the future. Please feel free to ask me any questions about the research or your participation in it. You can ask me today, or you can call me collect at any time at (510)528-4638.

I have read the above information and I am willing to participate.

Name _____ Date _____

Informed Consent Form for Physicians

I am Ori Tzvieli, a medical student at the University of California at Berkeley/University of California San Francisco Joint Medical Program. I am doing research on the care physicians give to patients with terminal diagnoses. I invite you to participate in my research but you are completely free to say no.

If you decide to participate, I will interview you for about an hour. I will ask your permission to tape-record the interview. I will ask you questions such as:

“What do you think your dying patients expect from you, the physician?”

If any question is too personal or if you just don't want to talk about something just let me know and we will move on. Talking about some of these issues may make you feel upset or sad. If you feel upset, please let me know and we will stop the interview. If I can do anything during the interview that will help your comfort please let me know.

I will keep all the information I get from you completely confidential by labeling it with a code rather than with your name. I will store the tape and transcript in a locked cabinet, and I will store the code list in another locked cabinet. I am the only one who will have access to the cabinets. I will not use your name or identifying information in any reports of my research. I will not share any of the information you tell me with any of the staff at any facility where you provide care.

There are no benefits to you for participating in this project except the opportunity to talk about your experiences. I cannot provide you with treatment or advice of any sort. However, I hope that this research will benefit patients and doctors in similar situations to yours in the future. Please feel free to ask me any questions about the research or your participation in it. You can ask me today, or you can call me collect at any time at (510)528-4638.

I have read the above information and I am willing to participate.

Name _____ Date _____

Informed Consent Form for Non-Physician Practitioners

I am Ori Tzvieli, a medical student at the University of California at Berkeley/University of California San Francisco Joint Medical Program. I am doing research on the care physicians give to patients with terminal diagnoses. I invite you to participate in my research but you are completely free to say no.

If you participate, I will interview you for about an hour. I will ask your permission to tape-record the interview. I will ask you questions such as:

“As a non-physician caretaker, what do you see as some of the main weak points of physicians as they deal with dying persons?”

If any question is too personal or if you just don't want to talk about something just let me know and we will move on. Talking about some of these issues may make you feel upset or sad. If you feel upset, please let me know and we will stop the interview. If I can do anything during the interview that will help your comfort please let me know.

I will keep all the information I get from you completely confidential by labeling it with a code rather than with your name. I will store the tape and transcript in a locked cabinet, and I will store the code list in another locked cabinet. I am the only one who will have access to the cabinets. I will not use your name or identifying information in any reports of my research. I will not share any of the information you tell me with any of the staff at any facility where you provide care.

There are no benefits to you for participating in this project except the opportunity to talk about your experiences. I cannot provide you with treatment or advice of any sort. However, I hope that this research will benefit patients and doctors in similar situations to those you have witnessed in the future. Please feel free to ask me any questions about the research or your participation in it. You can ask me today, or you can call me collect at any time at (510) 528-4638.

I have read the above information and I am willing to participate.

Name _____ Date _____

Audio Records Release Consent Form

As part of this research project I would like to make an audio tape recording of this interview and then transcribe it into writing. I would like you to indicate below which uses of the recording you agree to. This is completely up to you. I will only use the recordings in ways that you agree to. In any use of the recordings, your name will not be used.

- 1) The recordings can be studied by the researcher for use in the research project.

Initials _____

- 2) The recording can be used for scientific publications.

Initials _____

- 3) The recording can be used at meetings of scientists interested in the study of health.

Initials _____

- 4) The recordings can be used in public presentations to nonscientific groups.

Initials _____

- 5) The recording can be used in classrooms for presentations to students.

Initials _____

I have read the above description and give my consent for the use of the records as indicated above.

Signature _____ Date _____

Appendix C – Approved Human Subjects Protocol (#98-1-85)

- 1) **Title**: The Provider's Role in Working with Dying Persons: A Physician's and Patient's Perspective.
- 2) **Related Projects**: Not applicable.
- 3) **Nature and Purpose**: This project is intended to describe the emotional and physical support system available to dying individuals. Specifically, the study will aim to ascertain what both dying patients and their physicians expect of the physician who is involved with a dying patient. The research will use qualitative, semi-structured interviews to assess the circumstances surrounding the dying process of individuals dying in a variety of settings, including hospitals, homes, and long-term care facilities. I will conduct interviews with patients, physicians and nurses to compare and contrast the expectations and perceptions of actual care received by dying individuals with the expectations and perceptions of actual care provided of physicians. I intend to apply the results of these interviews to three current issues in the medical world: 1) The growing debate over end-of-life care in the United States, including physician-assisted suicide and the ambivalence of many physicians surrounding the role they should play in helping patients end their life. 2) The growth of the hospice movement and past identification of deficiencies in physicians' knowledge and attitudes as a major factor leading to inadequate palliative care at the end of life. 3) The spiritual support available to dying persons in various settings and the resulting stresses on patients and physicians.
- 4) **Subjects**: The subjects of this study will include three groups, with the aim of 5 to 10 subjects in each group:
 - A) **Dying Patients**: Individuals who are diagnosed with a terminal illness (e.g. cancer, AIDS) who have been told that they are expected to live for 6 months or fewer by a physician and have had at least one physician involved in their medical care since that time. Subjects must be 18 years or older and still legally competent. Patients may be uninsured or receiving Medi-Cal or Medi-Care benefits. The subjects may be considered vulnerable as they can often be expected to be physically infirm, possibly in pain, and psychologically dealing with issues relating to their dying. Since a primary goal of this research is to determine what dying persons themselves expect of the physician, no less vulnerable population can be interviewed. It is essential, therefore that participation by these subjects be completely voluntary and free of coercion. To ensure this, third parties not involved in the research project (see section 5 below) will initially do recruitment of these subjects; alternately, recruitment will be done through a poster. In addition, I (the researcher) must make clear to the subjects that their participation in the study is in no way connected to the quality or quantity of physical, psychological or spiritual care that they will receive from any individual or organization. I must obtain consent for the interview immediately prior to its beginning, and offer to take any possible steps to allow the participant to be most

comfortable during the interview. I must additionally make it clear that the participant may stop the interview at any time or refuse to answer any question that makes him/her uncomfortable, and that remuneration will be independent of these factors.

- B) Physicians: Licensed medical doctors who have had experience working directly with at least 10 dying persons within the last 2 years.
- C) Individuals who have had experience working with both physicians and dying individuals. Non-physician health care providers who have worked closely with at least 10 different physicians and dying patients within the past 2 years will be selected.

For all three groups of subjects there will be no selection criteria based on sex, race, ethnic group, cultural background, sexual preference or socioeconomic background.

5) **Recruitment:** Initial recruitment of the subjects will be done in two ways, according to their category:

- A) Dying patients will be recruited in two ways. With the consent of administration, a recruitment poster (see appendix A) will be posted at several residential hospices describing the participation as consisting of a one-hour interview conducted at a location convenient to them and compensated by a \$20 cash payment. Potential subjects will contact me by phone. Alternately, an administrator of home hospice care or a physician caring for patients in a hospital will be asked to identify individuals who may fit the research criteria and mention the study to these individuals. Potential subjects will be given a poster by the recruiting physician and asked to contact me by phone if they are interested in participating. All approaches to potential subjects by the recruiting physicians will occur only following a medical or hospice-related visit. When they contact me over the phone, I will assure potential subjects that neither any individual nor any clinic/hospital/hospice where they receive care will be told whether or not they chose to participate in the research.
- B) Physicians and nurses will be recruited through posters (see appendix B) posted at several clinics and oncology wards, with the permission of clinic administration. The poster will describe participation as consisting of a one-hour interview conducted at a site convenient to the participant and remunerated by a \$20 cash payment. Alternately, several health care providers will be asked to identify colleagues who fit the criteria above. They will mention the study to these colleagues and give them a copy of the recruiting poster with information on how to contact me if they are interested in participating. If the colleague indicates an interest in participating in the study and prefers to be contacted at home, recruiting providers will give the potential subject's home phone number to me.

Potential subjects will contact me by phone, at which point the telephone screening will be performed (see Appendix C). If I approach the potential subject by calling them at home (only for subjects in categories B or C), I will do the telephone screening at that time. If the screening criteria is satisfied and the subject remains interested in participating in the research project after receiving the proper information at the telephone screening, a day, time and place for the interview will be agreed upon

over the phone. If the subject is a dying person, I will make arrangements to call the day prior to the interview to confirm the patient's willingness and availability at that time. The informed consent and audio records release consent forms will be given to the subject immediately prior to the interview. I will offer to read these out loud to the subject. At each point of contact with the subject, I will reconfirm that the subject is still interested in participating in the research, and will reiterate their option of stopping the interview at any time or not answering any particular question.

- 1) **Screening Procedures:** The screening criteria will follow the guidelines for subjects presented in section 4 above as determined by the phone script (see appendix C). Once I have explained the project to the potential subject over the phone, I will ask the subject if he/she wants to participate. I expect to interview every interested potential subject who fits the criteria above and for whom a mutually agreeable time and place for the interview may be arranged. If the potential subject chooses not to participate, the record of his/her name and phone number will be destroyed.

- 2) **Procedures:** I will interview the participants alone in a private room for one time only with no follow-up. The location of the room will be determined by convenience to the subject. If possible, I will attempt to interview the patient in a room away from a hospital or clinic in order to protect their confidentiality (e.g. in their home or at a University building). Where physical condition limits the subject's mobility I will interview them in their hospital room, but will take every possible measure to ensure their privacy, including asking them if they wish me to take any additional steps towards insuring their privacy. The location will be mutually agreed upon in the phone screening prior to the interview. I will emphasize that participation in the interview is in no way connected to other services the subject may receive from any individual, organization or facility. The interviews will last about one hour and be conducted in English. Informed consent for the interview as well as permission to (audio) tape-record and transcribe the interview will be sought both on the phone and immediately prior to the interview. The subjects will be reminded several times that they are free to stop the interview at any point, or to decline to discuss certain issues.

My role throughout the interview will be to pose questions and ask for clarification; I will not offer any interpretations or counsel or advise the subjects in any way. I will not seek any opinions about the character or care of the subject from any other person or from any written materials. The questions that will guide the interview are attached in Appendix F

- 3) **Benefits:** There are no direct benefits to the subjects of this study other than remuneration. Indirect benefit may result from increased understanding of their situation arrived at through the interview. There are potential benefits to society from this research; the benefits would result from medical and health care professionals gaining a greater understanding of the expectations dying individuals may have of them through the dying process. Health care professionals and students may also gain an introspective understanding on how aspects of their behavior can be perceived by dying patients and other hospital staff (both helpful and unhelpful behaviors). Thus,

they can develop methods of care and referral that are more attentive and compassionate to the needs of dying individuals. Individuals who are dying may also benefit from reading this research in as far as it helps them articulate their experience of others as mirrored by others. This may help them articulate their own experience, needs and expectations to the individuals caring for them, particularly physicians. Social discourse of this research may help advance the discussion on hospice and palliative care and the needs of dying individuals in general.

- 4) **Risks:** There are no physical risks to the subjects in this study. Drinking water, unless medically contraindicated, will be provided in all interviews to minimize hoarseness and throat pain/dryness. Social risks are also minimal due to the limited nature of the study and the provisions for confidentiality. However, there are certain psychological risks. A subject may become distraught as a result of discussing unpleasant feelings or experiences. He/she might become aware of distress in a way that he/she may not have noticed before. The subject may also become more worried about his/her physical or psychological health. If the participant becomes distraught the interview will be immediately stopped.
- 5) **Confidentiality:** The interviews will be numbered chronologically and a fictitious name will be used if the subject is referred to by name in the final study. The tape recordings and transcriptions will be stored in a locked cabinet; records of the subjects' names and phone numbers will be stored in a separate locked cabinet. Information disclosed in the interviews will not be shared with the subject's physician or care-facility staff. The participants will be informed of all of these provisions for confidentiality.
- 6) **Informed Consent:** Please see the attached informed consent form in appendices D and E. These forms will be presented at the outset of the interview, and I will offer to read them out loud to the subject and to answer any questions about the forms or the study. The participant will sign two copies; I will retain one of the copies and give the other copy to the participant to keep for his/her records. The consent form will describe the purpose and format of the study, risks and benefits, provisions for confidentiality and remuneration. The form will state that the subject may terminate the interview at any time or refuse to answer any questions. The sensitive nature of some of the questions asked will also be described. Consent will also be sought to tape and transcribe the interview and to use the material for research. I will keep consent forms for a period of three years after the completion of the project.
- 7) **Financial Aspects:** Subjects will be given a \$20 payment to participate in the study. They will be informed of this remuneration on the recruiting poster or by the recruiting individual, by phone during the initial screening, and again at the outset of the interview. They will be informed that stopping the interview at any time or refusing to answer any questions will not prevent them from receiving the payment. The payment will be given at the end of the interview, or earlier, if the interview is terminated by the participant.

8) **Written Materials:** See appendices below

A Sample Recruitment Poster for Dying Subjects:

Have You Been Told By a Doctor That You Have
Less than 6 Months to Live?

Do You Work Closely With A Medical Doctor in
Treating or Caring for Your Illness?

If you answered yes to both of these questions than

YOU ARE INVITED TO PARTICIPATE
IN A RESEARCH STUDY ABOUT THE
RELATIONSHIP BETWEEN PATIENTS
AND DOCTORS.

What Participation Involves:

A one-hour private interview done in a location convenient to you. You will be asked questions about your illness and what it means to you. Other questions will be about where and how you receive care and how you feel about the care you are receiving. The interview will be entirely confidential.

The study is being done by a medical student at the University of California at Berkeley who is doing research for a Master's degree.

If you are interested, please call Mr. Ori Tzvieli COLLECT at (510)528-4638 to learn more and schedule an interview

Note: Participation in this study is not a medical treatment. Participation in this study will in no way affect your ability to receive medical or other services from any facility or organization.

A Sample Recruitment Poster for Physicians/Nurses:

**Are You a Physician, Nurse or Other Health Care
Practitioner?**

**Have You Cared for Persons Diagnosed with Less
than 6 Months to Live?**

If you answered "Yes" to both of those questions than...

**YOU ARE INVITED TO PARTICIPATE
IN A RESEARCH STUDY ABOUT THE
RELATIONSHIP BETWEEN PATIENTS
AND DOCTORS.**

What Participation Involves:

A one-hour private interview done in a location convenient to you. You will be asked questions about your experiences with dying people and what they mean to you, where and how you provide care, patient expectations, and patient satisfaction with the care they receive as they near death. The interview will be entirely confidential.

The study is being done by a medical student at the University of California at Berkeley who is completing a Master's thesis.

If you are interested, please call Mr. Ori Tzvieli COLLECT at (510)528-4638 to learn more and schedule an interview

Phone "script" to be used by me when making the initial contact with potential subjects.

When receiving a call:

- 1) "Hi. Are you calling about the research study I am doing about the relationship between patients and doctors?"
If "Yes,"
- 2) "Hello. My name is Ori Tzvieli. I am the person doing research on the relationship between patients and doctors. Are you still interested in participating in this research?"
If "No," thank person and end conversation.
If "Yes" ask:
- 3) "Are you someone who has been told by a physician that they have less than six months to live and are you still under the care of a physician?"
If "Yes," skip to #5.
If "No," ask:
- 4) "Are you a health care provider who has worked with persons who have less than six months to live? Have you worked with at least 10 such persons in the past two years?"
If "No," thank person and end conversation.
If "Yes," say:
- 5) "I'd like to tell you a little bit more about the research study so you can decide if you wish to participate or not. I am a medical student at the University of California at Berkeley/University of California at San Francisco Joint Medical Program. I am doing this study as part of my master's thesis project. I am interested in finding out how satisfied people are with the care they receive from their doctor after they are told they have less than 6 months to live. I want to compare this to what doctors think they are doing well and find out ways doctors could do a better job at caring for people at the end of life.

(The following section will vary with according to the subjects' category)

If you participate in this study, I will interview you for about an hour about your illness and what it means to you and about the care you are getting.

----- Or -----

If you participate in this study, I will interview you for about an hour about your experience working with dying people and what it means for you.

----- Or -----

If you participate in this study, I will interview you for about an hour about your observations regarding the relationship of physicians and patients who are dying.

(End of variable section)

I will meet you at a location that is convenient to you at a time that works well for you. I will give you a \$20 cash payment to thank you for helping me with my research. If you would like and if I can reach you by phone, I will call the day before the interview to confirm that the time still works for you and to make sure you are still interested in participating.

Some of the questions in the interview might be kind of personal or difficult to answer. You can tell me at any time that you don't want to answer something or that you want to stop the interview. I will give you the payment even if you stop the interview or