False Expectations: Patient Expectation and Experience of Dying in a Biomedical Community

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It is widely recognized that the role of the physician has undergone dramatic changes in the last century – changes which have serous implications for the patient-physician relationship. This is an ethnographic study examining how certain changes in the role and abilities of biomedical physicians have affected patient attitudes and expectations about end-of-life care. In-home interviews were conducted with eighteen persons age fifty-five and older, including a sample of Hemlock Society members. Results indicate a broad spectrum of end-of-life concerns including capacity, autonomy, pain, and burden to loved ones. Most participants reported a reluctance to begin a discussion of death or future deteriorating capacity with their physicians. Instead, when conversations about death were reported, they had been largely limited to the scenarios of catastrophic illness (e.g., hospitalization, ventilator, etc.) and the Living Will. While this discussion does not overlook the utility of the Living Will, it proposes that reliance on this document for preparing patients for end-of-life care is inadequate.

INTRODUCTION

As biomedical practices have changed during the 20th century, how have patients responded to these new experiences of biotechnological healing and life preservation? Though numerous perspectives on the impact of developments in biomedicine have been published in recent decades, patient perspectives are not often among these. This study documents lay perceptions of biomedical technology and practices for end-of-life treatment and how these impact a patient's approach to death and dying. I build on works such as Deborah Gordon's "Tenacious Assumptions in Western Medicine" (1) and Muller and Koenig's discussion of Dying and the Culture of Biomedicine (2), in which various points of convergence and divergence between professional and patient biomedical ideas about of death are exposed and analyzed.

This research is an investigation of patient perspective on biomedicine's approach to death.[1] I focus specifically on patient narratives to induce larger arguments about biomedical principles of death and dying. Addressing these principles, Jean Comaroff argued that biomedical practice is based on a *polarization of* life and death, whereby "life came to be synonymous with organic structure and function and the life span of the physical body, while death came to mean the 'end-state', the structure of life" (3:367). The physical body became increasingly central in ideas about health, life, and death. Patients' understanding of death and the dying process became so strictly informed by biomedical concepts of illness and capacity that, as Arney and Bergen have stated, "Today we cannot think about death except in a language informed by medicine" (5:37). Why is a better understanding of this process important to medical anthropology? If Litva and Eyles are correct, that "the shape of the health care system is, in part, dependent on how health is viewed by users of the system" (6:1083), then patient perspectives and preferences both index and inform biomedical ideologies and are important areas for research.

A patient perspective is emphasized for several reasons. Global changes have altered the way humans are dying; people in the U.S. are dying of different diseases, at a much older age, in a different place, with different ideas about how the experience should occur. The medical and legal concerns over patient rights in end-of-life care have recently received the lion's share of attention in mass media as well as clinical and legal journals (7,8). What is missing, however, and what medical anthropology may provide, is a multi-faceted investigation of the patient's beliefs and values around death, inclusive of their environment, decision-making processes, priorities, and expectations.

The paper begins by placing the biomedical practice of end-of-life care in historical context. There is tremendous variety within this "practice", both now and throughout its history; but several cultural, political, and scientific trends have contributed to biomedicine as it is practiced today in the United States. In the section titled "Background for a Study of End-of-Life Health Care Decisions," I describe some of the

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[1] Throughout this paper, I use the term 'biomedicine' to refer, in Kleinman's words, to "the biomedicine of knowledge creators (researchers, textbook authors, teachers) and of the high-technology tertiary care institutions that dominate medical training and that represent high status in the profession" (3:25). There is thus a risk of totalizing statements about a "homogenous social reality" (3:23) which I hope to avoid through specific and contextualized ethnographic description.

attitudes and practices within biomedicine's history, how these affect modern biomedical care, and the epidemiological context which makes end-of-life health care issues of such importance now. Next, I discuss the ethnographic research which will ground my discussion. I will contrast the themes of the interviews with the professional beliefs and practices reflected in the literature, illustrating some significant conflicts within end-of-life care. Differences between patient experience and expectation implicate more than problems with individual physician-patient relationships; they reflect structural and systemic conflicts within biomedicine around how and for what patients should be informed and prepared. As patient experiences of illness and death have been changing this century, are their expectations subsequently being brought "into line"? Or is mental and emotional preparedness unnecessary or irrelevant to end-of-life care? The results of this research indicate one set of answers, and speak to how biotechnological achievements might be aligned with the older art of patient care.

BACKGROUND FOR A STUDY OF END-OF-LIFE HEALTH CARE DECISIONS

Dr. Lewis Thomas has said that the reputation of 19th and early 20th century physicians rested on timing and charisma, more so than their relatively ineffectual clinical intervention (9). Most services were rendered in the patient's home, as physician clinics and hospitals had not yet become popular, and fees were often paid in-kind. Starr, whose The Social Transformation of American Medicine (10) is one of the most comprehensive social histories of the biomedical profession in the U.S., attributes these characteristics of the craft to 19th century market features, including a smaller profession, less demand for medical services, and greater reliance on family and home-care during illness. As the number of physicians grew and access to them became easier through improvements in transportation, the high demand for medical care encouraged the development of hospitals and immobile physician practices. Care for the ill and dying was increasingly moved away from the home and family into professional medical institutions.

It was an era of techniques such as cupping, powerful emetics and cathartics, and bleeding of the patient until they became unconscious if necessary. These medical techniques have since been called "heroic measures" for the courage of the physician to perform them and for the stamina of patients who endured them (e.g., 10:42). This heroic positivist philosophy of medicine, in which physicians are still indoctrinated, idealizes the extension of life at almost any cost. The relative impotence of medicine before this century led physicians, whose schooling and

practice were standardized only late in the 19th century, to take extraordinary risks in the effort to save a life which would otherwise certainly be lost. This is not to say that physician practice was without caution, but contextualizes the use of what seem today extreme techniques. To diagnose a patient as dying created a different set of challenges. Regarding death, Dr. William Osler (1849-1919) was concerned "that excessive medical treatment simply to prolong the patient's life might even lessen the patient's quality of life" (11:639). The crux of the problem for Osler's generation was determining *when* the ghostly line between life and crude physiologic existence had been crossed by a patient.

We have not found a reliable resolution to the problem of when *not* to treat a patient despite our vastly improved technology. Osler simply clarified that death was not *only* a problem of biomedical technology but a problem of diagnosis. Certainly, a physician's duty is to place a substantial obstacle between the patient and death, but when death is imminent or simply preferable to the pain, cost, loss of mobility, etc., what, then, is the physician's role?

Physicians now use the term "futility" to describe the effect of treatment which should not be performed (12,13). But there is ambiguity around the invocation of the term, and although it is an acceptable criterion for withholding treatment, futility in clinical cases is very difficult to define. It involves not only institutional (e.g., hospital) definitions but the decision of each physician in each scenario. Also, as new life-saving remedies or treatments are discovered, death is re-defined. In a commentary on the elusiveness of the term futility and the need for the medical community to come to agreement on the term, Schneiderman and Jecker acknowledge:

> It is important to note that we believe that, as in the case of the definition of death, the medical profession at best can *propose* a definition of futility, but ultimately society at large will *decide* the definition of futility. (12:437, emphasis in original)

Futility, the diagnosis that a patient is dying and nothing else can be done, is thus culturally constructed. Although physician skill and biomedical technology can alter the course of disease or its symptomatology, it remains a social process as to what death means. Biomedical definitions are included in this social process in the sense that death is considered only in relation to biomedicine's ability to intervene.

EPIDEMIOLOGICAL CONTEXT OF DEATH IN THE 1990S

Several precursors to today's tumultuous death and dying debates can be identified. Reductions in mortality worldwide have occurred this century as a function of several factors including: improved infant mortality; reductions in mortality from infectious disease; and declines in the mortality rates of the major degenerative diseases (14, 15). Public sanitation improvements and "physical hygienism" (16) in the late 19th century were major contributions to improved health patterns. The pandemics of infectious and parasitic diseases claimed fewer lives, more children survived into adulthood, and degenerative diseases became more significant in mortality rates. This is the epidemiologic transition about which Omran wrote (17). The result has been a compression of mortality into the older age groups, as well as an extension of "old age" into later decades. Currently, the size of the U.S. population over 65 is roughly 34 million people, or almost 10 times the number at the beginning of the 20th century. These numbers represent not only more young-old (ages 65-75), but more middle-old (ages 75-85) and oldest-old (ages 85+). The number of centenarians has almost doubled each census year since 1950 (14:96) (see Figure 1, adapted from 14:17).
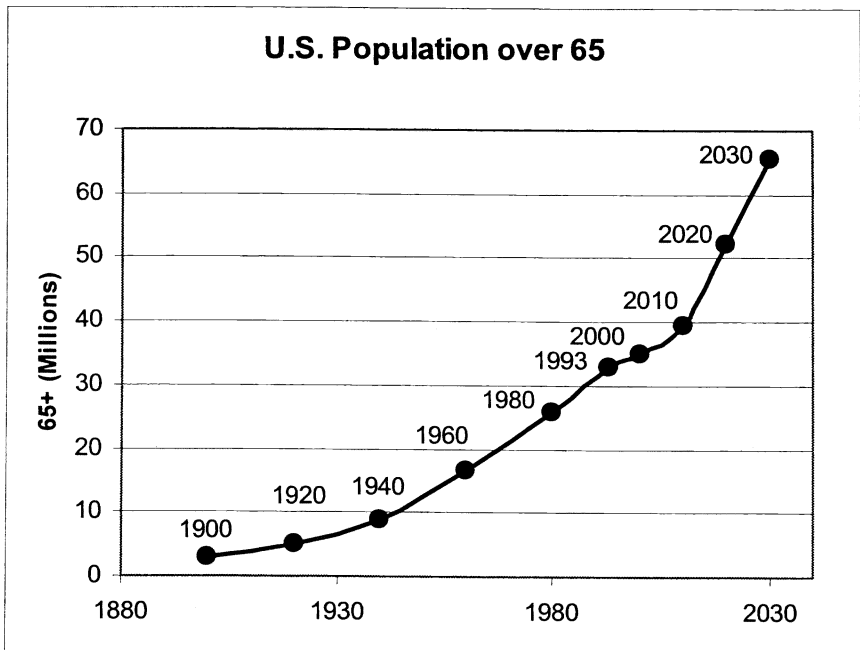

Table 1 (adapted from 14 and 18) indicates the ten leading causes of death. The primary killers in 1900 were infectious diseases with sanitation-related diseases also prevalent in the top ten. By 1995,

however, degenerative diseases have clearly moved into prominence. Influenza and pneumonia (combined) went from being the most common causes of death at the turn of the century to sixth, after several degenerative (or "old people's") diseases and accidents. As heart disease, cancer, and stroke have become the major causes of death, we are seeing corresponding changes in the dying experience. These degenerative diseases strike at a person's mobility, strength, dexterity, and senility in slow progression. Today's more likely end-of-life health care scenarios are described, for example, by Dr. William Knaus who conducted a 4 year study on the experience of terminally ill patients (19). Dr. Knaus found that half died in "moderate or severe pain" and that more than 1/3 "spent 10 or more days in a coma, attached to a ventilator, or in intensive care where they often were isolated from their families" (19:32).

TABLE 1: LEADING CAUSES OF DEATH 1900 VS. 1995

Rank	1900	1995
1	Influenza and pneumonia	Heart Disease
2	Tuberculosis	Cancer
3	Gastroenteritis	Cerebrovascular disease
4	Heart disease	Pulmonary diseases
5	Cerebral hemorrhage	Accidents
6	Chronic nephritis	Influenza and pneumonia
7	Accidents	Diabetes
8	Cancer	HIV
9	Diseases of early infancy	Suicide
10	Diphtheria	Chronic Liver Disease

According to epidemiological trends, then, we are predisposed in old age to a slow, degenerative process of dying. One result of the extension of life into later decades is that most Americans have been able to plan on a long life. Recognizing the detrimental impact of a delay of planning for the dying process, Restrepo and Rozental write:

> Issues of the aged are generally not addressed by most individuals during their life course, but are left to those primarily concerned. This process tends to alienate individuals from understanding, becoming involved, and planning beyond their immediate circumstances (20:1328).

Evidence from the research detailed below will support the claim that consideration and planning for death is often delayed until late in the life course, and that specific and detailed discussion of the goals and possibilities during the end of life are often never fully considered in advance of illness and incapacity.

INTRODUCTION TO THE RESEARCH

This investigation of death and dying began with a question into how people want and expect to die, when their primary healing system of choice is biomedicine. I recognized that the results of my research would reflect only a part of the process, interactions, and experience of dying, and would therefore not reflect the diversity and breadth of patient experience. I therefore tried to build the research instrument into one that would explore extreme conditions; one that would expose assumptions about extreme health care scenarios and extreme positions on dying.

I chose two groups of participants: patients from one geriatric practice in Tucson, and members of the Hemlock Society. I compared these two groups for converging and diverging responses, looking specifically for ideas about how death should occur, who should be involved, and what role biomedicine should or would play. As I stated earlier, my expectation was that Hemlock Society members would express a greater sense of preparedness for likely end-of-life health scenarios caused by chronic and degenerative diseases. This expectation was based on the Hemlock Society's self-portrayal, as well as the media portrayal of this organization, as a right-to-die (assisted suicide) political action group. Even the least active members, I thought, would have considered that a natural death might occur later than they would have preferred. Members had (1) made an open statement about their wishes for the dying process; (2) considered to some extent the conditions under which they would prefer to die, that life would not be worth living; and (3) were willing to discuss these views with not only Society members but with a stranger under the auspices of research into "beliefs about death and dying". For these reasons, it was expected that Hemlock Society members would provide quite different responses to questions about expectations and experiences of death than non-members.

METHODOLOGY

The ethnography involved open-ended interviews with persons in various states of health, all utilizing some type of biomedical services or care. Participants were asked to speak about their perceptions of biomedical care and the role of physicians and others in health care

decision-making at the end of life. Health-seeking strategies and plans were discussed, as were their reported experiences with doctors, their values and attitudes about death and dying, the information they were given or obtained on treatment options, and their opinion about those options. (See Appendix A for Interview Questions.) A total of 18 patients[2] were identified in Tucson, Arizona, limiting participation only to persons age 55 or older and English-speaking.

THE RESEARCH COMMUNITY

Tucson, AZ was considered a logical site for this study of aging, health care, and dying. Arizona is a popular retirement location due to the "weather, quality of life, and the presence of friends and family" according to a 1997 report by the Arizona Chamber of Commerce, Office of Senior Living (21). The 1996 Arizona Census reports Tucson's population at 776,000. Approximately 14% of this population is 65 or older (roughly 108,000 people). Arizona is a leading state in the number of managed care organizations, many of which are owned by practicing physicians.[3] Since 1991, Tucson has added headquarters for HealthPartners Health Plans and Olsten Health Services and was already home to more than 10 health care corporations.[4]

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[2] A total of 18 participants were interviewed, six of whom were interviewed in group format as part of the focus groups. Since several of the questions utilized in the focus groups matched those used in the individual interviews, the focus group narratives were retained for analysis.

[3] HMOs and PPOs with offices in Tucson include: Blue Cross Blue Shield of Arizona; CAPP Care of Arizona; CIGNA HealthCare of Arizona; FHP Health Care; Human Health Care Plans; Intergroup of Arizona; Partners Health Plan; Southern Arizona Physicians Service Association; and The University Physicians in Association with Regional Healthcare Group.

[4] These include: Carondelet Health Care Corp.; University Medical Center; Regional Healthcare Serv.; University Physicians, Inc.; Columbia Northwest; Thomas-Davis Medical; Columbia El Dorado Hospital; Intergroup of Arizona, Inc.; HealthPartners Health Plans; CIGNA HealthCare; NextHealth Inc.; El Rio Health.

PARTICIPANT SOURCES

Given the small size of this study, efforts were made to select participants with a range of characteristics in socioeconomic status, health status, general amount of biomedical care utilized (e.g., annual or every month), sex, educational level, and age. The cut-off age of 55 was utilized simply to acquire participants who had begun to consider the issues of retirement, aging, and death. Participants were of various Anglo-American descent.

The sources for patients were the Southern Arizona Chapter of the Hemlock Society and patients of one physician specializing in geriatric medicine. The Hemlock Society offered a local comparison group that could be identified specifically for their attitudes about death and dying and for a political action agenda. The Hemlock Society mission statement reads:

> The Hemlock Society USA believes terminally ill people should have the right to self-determination for all end-of-life decisions. Because Hemlock reveres life, dying people must be able to retain their dignity, integrity and self-respect. We encourage, through a program of education and research, public acceptance of voluntary physician aid-in-dying for the terminally ill.

The Hemlock Society is explicitly a political action organization and does not involve itself in any kind of treatment interventions. At most, the Hemlock Society offers new members opportunities to purchase literature on "how people may take their own lives, and how far others may go in helping without breaking the law" (22). While the experiences and opinions of its members cannot be singularly portrayed, the Hemlock Society mission is utilized in this research as an ideological extreme against which to compare modern beliefs and attitudes about the dying process.

Seven participants were Hemlock Society members. The remainder of the sample (n=11) came from the patient caseload of the Home and Community Based Services clinic at Kino Community Hospital. Patients were chosen based on the physician's assessment of patient willingness to complete the interview, as well as their physical and mental capacity to do so. Appropriate informed consent and permission were received prior to interviews[5]. Participants were asked to allow the interviewer into their home at a time convenient to them, and were asked to prepare for a private conversation, although twice care givers remained present.

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[5] University of Arizona Human Subjects Committee, Pima Health Services (Kino Community Hospital) Internal Review Board, and individual informed consents from all participants.

Discussions about death and dying are challenging for everyone. The research interviews not only involved patient narratives on a wide variety of personal subjects, but many of the participants were seriously or chronically ill and uncomfortable due to pain, restricted breathing, or immobility. Many participants cried at some point during the interview. Remarkably, participants did not shy away from the questions after becoming upset but continued with the interviews in every instance. As Harty-Golder (22) describes, patients *want* to discuss these issues with their physician and have questions or concerns that are often unvoiced if no invitation is made by the physician to discuss death and dying. As I will argue, the Living Will discussion only raises issues around extreme end-of-life circumstances requiring significant mechanical intervention. It does not raise awareness of other concerns including physical and mental deterioration and loss of independence.

The research participants were interested in the questions and often heard their own contradictions (e.g., first stating they would kill themselves before requiring in-home care but later identifying whom they had chosen to live with after they could no longer take care of themselves). They used the ethnographic interview process to verbalize and produce their own beliefs about death, rather than already having developed them. But these discussions took a significant amount of time to produce: time which many physicians, according to participants, do not have or take. If the dialogue itself is critical to patients' discovering and creating their ideas about death and dying, then should this process be a more clear and consistent element of therapeutic practice? What responsibility can or should physicians take for patients' experience of dying? By segregating the body and its experiences, modern, specialized biomedical practice ignores the need, and patients' demands, for synthesis.

THEMES: CONTROL, CAPACITY, BURDEN

Several themes emerged from the narratives of participants, including some which were unexpected. It became apparent that expected differences between Hemlock Society members and non-members (in preparedness and plans for dying) were not evident in the interviews. The issues of control or autonomy in health care decisions, physical and mental capacity, and the burden that a participant's health care might place on significant others were consistently raised within the interviews. Further, not only do physician attitudes and manner play a significant role in participant health care seeking and decisions, but the opinions and behaviors of significant others are also considered on an ongoing basis.

As the age and health of these elderly reduce their mobility, they experience decreased independence and greater difficulty and fatigue with daily activities. When family is not available to buffer them from these losses, the elderly are at risk for isolation. EB seemed and expressed that she felt particularly isolated since her hip and heart surgeries in recent years.

> EB: I'd go down every day to the rehab. ... (but) I haven't been up to it. I'd have to have somebody drive me there. I'd have to wait for the Handi-Car (service). Wait two hours for them to show up.

And SB summarizes her experience of isolation well:

> SB: How quick things can change! Like that. I told my daughter, you don't know what shock is when you give up your car, apartment, everything.

Even the process of accepting care from a hospice program can be inconvenient and frustrating as for RL, a 65 year-old woman whose significant medical problems did not rob her of her desire to plan her own daily activities. In the following excerpt, she is speaking with a 64 year-old Hemlock Society member who, incidentally, is in excellent health.

> RL: I'm in a hospice program (which means a social worker visits me three times per week).... That's three days out of my life that I don't do what I want.
> VF: And I would resent that.
> RL: I do, I do... I don't know how many more (days) I'll have. And I do, I want to go to the show Monday... and they call up without any notice, and they're coming. And I think, well, I was going to go to the show....
> VF: Why don't you tell them that?
> RL: Yae, well.... I can't say no to anybody

For most, the experience of losing control over the material or logistical aspects of one's life is an increasing irritation. But for some, it can be overwhelming. The woman quoted below, whose health is poor but not imminently terminal, took particular pride in describing her years of work to support a sick husband and her children. MK's primary concern was not her medical ailments, of which she had many. At age 78, MK was reflecting on her life and her experiences. She told long, detailed stories of her husband's illnesses and her duties as his nurse and income provider to the family. She would neither be rushed nor cut off during her interview, displaying the resolute yet generous character that was portrayed in her narration. Autonomy for MK was not simply maintaining her home, but being in control of it as well.

The home MK had paid for and now lived in had come to symbolize not only her independence but the purpose and value of her life. When confronted by medical bills which required her to relinquish this home (which would occur only *after her death*), the loss was too great for her to bear. She grieved this loss, and wished for her own death, during the interview:

> MK: Look, for 32 years, I've worked 16, 18 hours a day. What did my home mean? A place to sleep, rest. ... I want the peace and quiet. If I want to eat, I eat. If I don't, I don't. And for them to tell me, when my Case Manager came and said, they're waiting for you to sign over the house to bill collectors - (breaks off, crying).

This woman went on to say she wanted a "one way ticket to Michigan" for Dr. Jack Kevorkian's help in an assisted suicide. She was not a Hemlock Society member. She simply had been unable for several days to find value in living if her home, a large factor in and symbol of her independent identity, were to be taken by bill collectors, even if only after her death.

Hemlock Society members were most clear in their statements about autonomy. Most had joined this organization based on a fear that decision-making power would be taken from them in end-of-life health care decisions. EB's statement is typical:

> EB: I believe that I should have the right to decide how I want to die. I feel very strongly about that. And I have done everything I know to this point to let all of my family and my doctors know that's where I'm coming from.

In sum, a person's ability to exercise autonomy depends on several things. Physical or logistical circumstances can limit a person's mobility and/or access to resources such as transportation. The psychological state of a person impinges on their priorities, as in MK's case above, which in turn can profoundly affect patient health-care decisions. Hemlock Society members discuss many of the societal factors that affect autonomy including the legal limits to personal choice. And finally, relationship factors were also relevant to participant autonomy because, despite the fact that participants often stated an intent and/or desire to be autonomous, they had not made these decisions in a vacuum of interaction. Decisions to live alone (for both Hemlock Society members and non-members) were made based in part on evaluations of whether family members could or were willing to care for them. These relationships and their impact on health care decisions is discussed further in the next section.

HOPES FOR CAPACITY

A second theme throughout the interviews was in the expressions of hope or a plan to avoid (further) pain or incapacity during the end of life. Participants were asked to specify what degree of pain or type of incapacity were intolerable. Their answers varied and often reflected a significant degree of ambivalence, as in the narrative of this very healthy and fully independent 75 year-old woman:

> RyB: There are times when I got to the thought, if I would come to that, that I couldn't walk, would I be ready (to die)? I wouldn't be ready then. Cause my mind, my mind is not, I could still do things otherwise with my mind that I couldn't do, maybe not walk but I could go do other things.

Having adjusted somewhat to life in a wheelchair, FD expressed his reliance on mental skills including his sense of humor:

> FD: Mental incapacity is much more difficult.... The mind can play awful things on a person. And if you've got that, your (physical) health will follow

But most are less concrete about which capacities are most important to their quality of life.

> SB: No, I wouldn't want machines.... You know, I never really thought about it. Probably if your mind wasn't there, it wouldn't bother you.
> HD: My fear is not being able to do for myself.... That runs wild in my mind. I don't know if I could handle (it).

In discussions of capacity, participants often expressed their tolerance of incapacity with respect to the amount of assistance from others they would require. There was a particular aversion to assistance in the areas of daily living such as bathing and using a toilet.

> RyB: I don't know as I have a thing about pain so much because I have a very high tolerance for pain.... More or less my first thing is that I would get down and not be able to, like I say, take care of my own needs. My own body functions and things like that.
> GW: I would not want to be that much of a burden to my daughter. I would prefer to go someplace, because I don't think that would be fair to her and her family to take on that responsibility of bed pans.

Like these two women (RyB and GW), almost all participants expressed a hope that their death would come before the need for so much assistance. But more consistently than any single capacity, participants expressed and displayed varying degrees of ambivalence on these questions.

Five out of the seven Hemlock Society members clearly stated their reason for membership was an aversion to life with incapacity and an intention to avoid it. This is remarkable since members appear more concerned with capacity, identity as an independent person, and burden to family/friends than with their *rights* under a specific diagnosis of "terminal" as outlined in the Society's credo. One very healthy, 75 year-old female member of the Hemlock Society voiced a common attitude of fellow members involved in this research:

> RyB: If I got down and required care, I would seek out someone that would
> help me end my life. I do not intend to be a burden to somebody else.

What seemed remarkable during the interviews on capacity was that participants frequently responded to specific questions about capacity with surprise or careful meditation, expressing that they had never before considered such specific health questions as: What type of incapacity, mental or physical, is worse to you? or, How much/What type of physical incapacity is tolerable for you?

> HD: Hmmm. I don't know. I never even thought about it I guess...
> Everything that's ever happened to me, there's always been somebody
> on my side. ... I've not talked to anybody about (death). *But I
> think I'm going to be here for 100 years yet.*

These reactions were particularly unexpected from Hemlock Society members, as it had been wrongly assumed that "right-to-die activists" would have considered a greater variety of health dilemmas as part of the membership experience. Yet even several Hemlock Society members stated that they had not considered what they would do, or how they would feel, in a scenario of slowly declining capacity or mobility:

> RuB: And I have concluded that I don't have a clue as to what I would do.... I
> am well aware that the decisions that I say I'd make now are in no way
> (a guarantee for what I would do in the future).

Hemlock Society members were *no more likely* to have considered death as a slow, gradual process of declining health and, in fact, were more likely to discuss dramatic, end-stage circumstances of the dying process such as extensive life support technology. When asked to discuss the somewhat more likely scenarios of slow degradation, most participants, Hemlock Society members and non-members, showed or stated they had not spent significant time discussing these ideas (e.g., the need for periodic oxygen or a wheelchair; full mental capacity with a need for assistance in bathing or toileting). Despite stated aversions to life with these conditions, participants typically did not consider them -

expecting life to either give them full capacity or catastrophic incapacity, in which the decision to die would be easy or clear.

As it became clear that the interview questions addressed topics in a detail and depth generally new to participants, it seemed that they would be unprepared (i.e., mentally and intellectually) for likely end-of-life health scenarios. The problem seemed to stem from the fact that details about likely end-of-life health scenarios (including the capacity, pain, and autonomy problems associated with chronic, degenerative disease) were not addressed as part of a Living Will. I discuss this finding further in my Discussion.

FEAR OF BECOMING A BURDEN ON FAMILY AND FRIENDS

The aging of the global population has required significant adaptation or replacement of health care patterns, social institutions, and technologies. Longer periods of old age before death indicate a need for many people to plan for an additional 20 years of post-employment living. Family structures have also changed with more care-taking being needed by grandparents whose chronic diseases are debilitating but not very quickly fatal. There will be fewer young to take care of the rising elderly population (age 65 and older), which will represent approximately 20% of the U.S. population by the year 2030 (24). Furthermore, even when children are available to care for aging parents, parents sometimes do not want to accept care from them, as one Hemlock Society member insisted:

> VF: It should not be (the children's) responsibility.

Her sentiment, although not universal, illustrates this century's decline in the "moral economy" of intrafamilial support. O'Rand et al's finding that U.S. family members are performing more care-giving is a reversal in this trend (25).

Participants' primary concern was with becoming a "burden" to family members. If a person considered elder care a positive experience, they were more likely to consider care for themselves. Those who discussed bad experiences with providing care for an elder in their life were often adamantly against accepting similar care themselves. RuB, who has provided care for many family members including parents, expressed the conflict:

> RuB: Cause I kind of believe in doing for a person while they're alive, and what can you do for em after they're gone?.... People just don't have that sense of responsibility towards your parents I guess, or something like that.... (I think of my own mother), and could I have worked her in? That sounds very cold when I say that, but that's really what you, when

you come right down to it, was I willing to give up some of my activity to take care of her and everything?

What emerged as participants discussed their priorities for end-of-life care were life histories and significant events that shaped these priorities. When participants discussed having seen the suffering of another friend or family member, they generally indicated not wanting to go through the same suffering. They also discussed their own burden of having cared for an ill family member and not wanting to put the same burden on their children.

> MD: So then my sister-in-law.... She couldn't live really alone, you know. Well she was for a while, then she got bad. So then we (my husband, son, and I) closed up this house and we rented a house in the foothills and we all stayed out there. Then she really got bad. And she would get belligerent and we couldn't find anyone who would come in and help. We tried to do things with her, you know, do things. And she was a person that was really brilliant when she was normal.... She made our life miserable.

Even those currently living with children (n=3) indicated a willingness and desire to move to a professional facility if they lost significant physical function (e.g., bowel and bladder control). But these same participants also stated that they hoped they would die before that happened.

> AJ: I wouldn't want to go and put the kids in debt. Cause I think when I get to the end, the quicker it happens the better. Then it would... that's always my thought: putting them in expense.

> RyB: And if I found that it really was, that there was no possible cure for it or anything else, ... I would seek out someone that would help me end my life. I do not intend to be a burden to somebody else.
> MD: I would rather be dead than be a vegetable.

Of course, the priorities of autonomy, capacity, and burden are very much interwoven and change over time and with each health care event. The interview questions led participants to compare their definitions of a quality life with various scenarios of health and capacity. In so doing, a majority of participants considered circumstances that they had not before thought of. In this way, they were forced to review, for example, how reduced mobility could affect their autonomy significantly *yet not so much that they would wish for death*. Others confronted feelings of pride or resentment for having cared for a loved one, while facing the possibility of needing such care for themselves in the future. History and relationships were thus also relevant factors in participant's opinions on each of these themes. In fact, for all the

common priorities of participants (control, capacity, burden), each carried a different weight depending on time and circumstances.

Most participants (n=14) identified one or more family members, including spouses and children, and friends as being involved in health care decisions, obtaining treatment, or discussing health and illness issues. Only one participant indicated that no one other than her spouse was involved in treatment issues: JB also reported that her family lived in another country and that she was raised to believe that "if you can't cure it, endure it", keeping "the proverbial stiff upper lip". Others chose to avoid health care and health care decisions:

> MD: I just send everybody else to the doctor. My son goes. I guess because
>   they went to the doctor so much and I was never ill. And I don't believe
>   in mammograms and I don't believe in pap smears. And if I ever got
>   anything, I wouldn't do anything about it anyway.

Some were eager for help. SB is an 85 year-old woman whose health is very good. When she fell and shattered her arm less than two years ago, her life changed dramatically. She was reliant on her daughter to help her negotiate the medical appointments and decisions.

> SB: Well, my daughter knew all this 'cause she was right there with me. I'll
>   giver her credit. And she works too. It was tough on her. I just couldn't
>   stand it if she wasn't there. She was smart too. Kept track of everything.
>   She was up on that, made sure that everything was taken care of.

With no spouse or other family members available for assistance with appointments and discussions with the doctors, SB has become reliant on one of her two daughters who, at the same time, cares for her own family.

Others had significant trouble accepting help. Another woman, whose health problems were life threatening, was somewhat more reluctant to accept the almost constant help and care that she needed from her husband:

> RL: Well, primarily when something comes up, (my husband) ... goes and
>   talks to Dr. --. I really don't like that. I'm used to talking to the doctor
>   myself. But now it's the case.

If neither a spouse nor adult children are available or considered appropriate, participants turn to friends. Professional care-givers are utilized (e.g., for in-home daily living assistance) but these persons were not identified by participants as part of the decision-making cohort.

The remaining participants indicated that only friends and no family members were involved in health care decisions, due to severed ties with

family members, geographic distance from them, or incompatible views with family which led participants to avoid their involvement in health matters. Those persons that participants think of as involved in decision-making are those with whom they have a personal relationship and history.

> FD: I haven't established too many friends out here. I'm happy where I am... I'm really not outgoing that way anymore. If I have to, I'll force myself but ... I'm happy in the kitchen with the history channel or, and a beer.
> RIB: I haven't really discussed (death) with very many people, you know, and I, in fact, that would be one thing that would keep me from going to a hospice, would be the fact that I don't want to spend the last days of my life sitting around with a bunch of other people who are dying.

During this discussion of health care decision-making, participants began to address their willingness not simply to *discuss* but to *raise the issue* of death and dying. Only a handful of participants stated that they had talked in depth with significant others. Participants indicated that they would not likely raise the issues but would wait for others, in the following case her rabbi, to approach them. This hesitancy is in spite of a great desire to discuss questions and concerns.

> RL: (Speaking about her rabbi) But they're no better... and he came once to see me and he called once. That's all... And I used to think he liked me.

It became quite clear during narratives that the quality of relationships, the comfort of the participant with a given friend or member, and the act of initiating discussion were critical to how death and dying would be approached. These findings support a claim that the meaning and experience of illness, and in this case death and dying, are in large part social products.

COMMUNICATING WITH AND GAINING INFORMATION FROM THE PHYSICIAN

The amount and type of information that patients obtain from physicians, or from any other of myriad sources, is an important area for investigation but has not been attempted here due to the enormity of such a question. This area of the study instead focuses on patient feelings of compatibility with their physicians: that is, the degree to which participants felt they could communicate with physicians on issues of death and dying, ask questions, initiate discussion, and obtain satisfactory answers or dialogue.

Since physicians were not interviewed, their practices and motivations had to be surmised from the literature. For example, some

authors state that the physicians' best tool in conducting delicate ethical and professional dialogues with patients is the way in which they control information (e.g., 26, 27). Information control is performed not only by those physicians wishing to control a patient's thinking concerning a certain treatment plan, but also for more altruistic purposes such as a physician's recognition of emotional distress and a desire to impart information to a patient in a sensitive manner.

Contextual factors that affect physician decisions about sharing information are many. The perceived emotional and physical ability of the patient to handle "bad news" is a primary concern of physicians who acknowledge and attend to the impact of psychological health on other conditions (e.g., 26, 28, 29, 30). Patient response may be mitigated by the existence of strong support mechanisms or a mental preparedness for bad news. However, these conditions are not always met or are questionably met, as far as the physician is able to determine. Ultimately, physicians must also consider the potential impact on the patient's life of the diagnosis, including stigmatization, implications for work or completion of family responsibilities, and the ability of the patient (e.g., monetarily, physically, emotionally) to pursue a desired treatment.

Some participants, particularly Hemlock Society members, adopted a proactive approach to their own health maintenance, using library and alternative sources of information. These participant narratives expressed a willingness to seek a physician's services but only after they had made relatively rigorous efforts to evaluate and investigate the probable causes of symptoms. These efforts, compared to some others' greater willingness to report all of their symptoms to a physician, often indexed emotions of fear, distrust, or aversion to the biomedical practices of diagnosis, "monitoring", and healing. This healthy 60 year-old and active Hemlock Society member stated:

> RuB: I don't like my body being monitored and I think that (my fear of going to doctors) is related to not wanting to find something wrong. ... I have trouble with the traditional view of the medical profession as being gods and all-knowing kind of thing. Yea. And so I make sure... I would immediately research it. That would be the first step, into the internet and into the medical library.

Information sharing is thus increasingly important to the patient-physician relationship as patients are adopting more proactive attitudes toward their own health and bodies.

> EB: Oh (my doctor and I) got along just perfect.... Because he liked me and I liked him.... Well, he had a great manner and he explained everything to me. Told me all about that defibrillator, how it worked, where he was going to get it from if he got it.

If physicians are reluctant to share and discuss health information and options openly with patients, many patients move to a different physician. Such a move can be particularly problematic for elderly patients with multiple medications and health problems.

> JB: No, I've never had a disagreement with a doctor. I disagree with their manner more than anything else. I'm an equal, and I have the final say and I am the arbiter. And on that basis is why I got rid of two doctors.

SB's comments below were echoed repeatedly by participants.

> SB: That one that I went to, I think he retired. I trusted him more than somebody else. [Why?] Well he seemed to be interested. You know, he cared. That's the main thing. He took care of you and he'd do something for you. I really believe... I don't think any of them do nowadays.

Since patient autonomy hinges on the information available to them, and since autonomy and independence are generally valued in the U.S., we can expect that the successful patient-physician relationships of the future are ones which foster patient autonomy through trust, information sharing, and open dialogue. The amount and type of information shared between patient and physician depends in large part on the compatibility of the two people. On patient-physician compatibility and its consequences, Abraham writes:

> There is good reason to believe that the poor and poorly educated have perhaps the least say of anybody in decisions about life-sustaining treatment. To begin with, most doctors relate better to patients whose backgrounds are similar to theirs (31:218).

The patient's comfort level, the physician's concern about litigation, and the sensitivity of the health matter— these matters directly affect the direction of a treatment plan. The relationship is, as one participant put it, "the essence of the thing. It's the absolute essence."

Several areas of the physician-patient relationship were explored. Participants were asked to tell a variety of illness scenarios, their own and others', from the course of their lives. They were also asked whether they had ever disagreed with the statements or recommendations of a physician. There were four participants who reported *no* negative experiences with doctors and denied ever being in conflict with a doctor's recommendations including these two men:

> FD: Unless I know differently, I'd put a lot of faith in (my doctor).... He's the boss and that's it.
> JS: Hey, (in the army, we saw) a scientific, a regular doctor, not somebody playing around. During the army, the regular doctors, they (were) all

MD's; wasn't a bunch of chiropractors, and the other ones, witch doctors.

Of the 14 who reported some negative experiences with current or past physicians, there did not seem to be a clear tendency to join the Hemlock Society (5 were members), have a Living Will (10 had Living Wills), or use alternative healers (7 had used a non-biomedical healer at least once). These results were somewhat surprising, since the existence of negative experiences with doctors was expected to correlate with a move toward alternative providers. Instead, participants seem to accept conflicts as an unavoidable part of seeking services from biomedical physicians, especially from health maintenance organization (HMO) providers.

In general, a patient's ability to state her/his treatment wishes may be made more difficult by fear, an inability to elicit relevant information from the physician, lack of knowledge about how to access care, and distracting symptoms of the illness itself. When critical information about symptoms or needs is not reported by a patient (who may not know it to have been critical information because of differing definitions of illness or interpretation of symptoms), the physician's ability to diagnose and properly treat is hampered. Take for example the following case described by HD.

> HD: Lately I want to be my own person. It takes me a while to complain to other people. Like with the hand situation, I went to someone in one of these... HMO's, and if you get (an emergency appointment) in between other patients, this one doctor, at least, seemed to resent it. And so the nurse, the triage nurse set me up something. It's not a scheduled appointment. (The doctor's) comment was "From polio leg to hands, what next?" So I thought that was... really weird.

This 75 year-old woman left the doctor's office that day very upset and, because of the inattentive care given, with two left wrist cuffs. She was forced to return for a right wrist cuff but never sought care from that physician again.

Options for dealing with conflict involved having a family member intervene or to switch doctors as with SB quoted earlier who "just couldn't stand it" if her daughter wasn't there to assist her and manage problems. Use of alternative healers was symptom-specific and mentioned only once as a direct alternative to the biomedical physician. Instead, when alternative healing methods were used, it was in conjunction with biomedical care.

It would be inaccurate to state that participants held unidimensional impressions of their physicians or of biomedical care in general. Clearly

the information contained in the narratives reflects only some of the participant's opinions at the time of the interview. In another setting, amongst different people, or after different health care experiences, the participants' responses would be different. Participants sometimes left room for their opinions to change, especially with regard to the important relationships in their lives. Participants were often aware of their own ambivalent feelings toward doctors and would humanize them through their choice of words or comparisons to themselves as "human beings".

> JB: I think ... the doctors in this country are very good. I think they're great men but they're not as great as they think they are. ... But still, as I say, they're a good bunch of people. It's the patients who are to blame as much as anything... "yes doctor, no doctor, three bags full, like a bloody load of sheep".

And even DF, who was very angry about her treatment and considered a malpractice suit, acknowledges:

> DF: To me, I treat them like they was human beings. That took me going to treatment, going to AA. They can fall down off a bar stool just as easily as I can.

Conflicts with physicians may thus be forgiven, or considered unavoidable, but they are not regularly resolved. All but two participants told stories of conflict with physicians that ended in a move to another physician. If poor physician-patient relationships have such a profound impact on a patient's willingness to be cared for by a physician, then there are almost certainly more subtle repercussions including the detrimental impact of poor communication.

Again, the process of the interview was meaningful in a number of ways. The experience of hearing, considering, and verbalizing answers to such strange and specific questions about death and dying was novel for most participants. They used the interview time to consider new options and to venture guesses about their likely behavior in a given scenario. In this sense, the interviews themselves became, for those moments, a part of each participants' therapy management process. By stating preferences to me, they were testing, or validating, health care decisions and plans which might be implemented in the future.

This finding points to the importance of dialogue in patient preparation for death and dying. Why do we see so much uncertainty and ambivalence in participants' discussion of dying, even among participants who have Living Wills and who are members of the Hemlock Society? To investigate this question further, a single but important communication event is discussed in the following Section.

BIOMEDICINE'S PLAN FOR DEATH: THE LIVING WILL

If professional and patient approaches to death are in any clear divergence, then I would argue that the Living Will exemplifies the division. The utilization of Living Wills is the primary, and often only, vehicle for discussions of death and dying between patients and physicians. Since 1992, it has been a federal requirement that all patients admitted to a hospital be invited to sign (or decline) a Living Will. It is a document which states an individual's desire not to be kept alive by "extraordinary means (i.e., life support systems and other machines which could keep a body alive for months and even years"...) (32). In addition, persons can create "advance directives" which can apply to any type of treatment decisions to be used in the event that they cannot voice or make medical decisions as they become necessary (33). The following excerpt from a standard Living Will contains the purpose and priorities of these forms:

> If I should, at any time, have an incurable condition caused by any disease or illness, or by an accident or injury, and be determined by any two or more physicians to be in a terminal condition whereby the use of "heroic measures" or the application of life-sustaining procedures would only serve to delay the moment of my death and where my attending physician has determined that my death is imminent whether or not such "heroic measures" or life-sustaining measures are employed. I direct that such measures and procedures be withheld or withdrawn and that I be permitted to die naturally (32).

This particular form does not attempt to further clarify "heroic measures" or the imminence of death. These determinations are left to the attending physician. Further, while it is an important (and legally required) tool for recording patient wishes in instances of terminal illness and significant, irreparable brain damage, the Living Will does not address most of the concerns of patients about degeneration, capacity, and end-of-life care. Studies have identified "loss of dignity", "fear of a loss of control or of dignity, of being a burden, and of being dependent" as primary reasons for requesting assisted suicide (34). If the central themes of the Living Will, which structures physician's approach to end-of-life care discussion, only broadly address the issues identified by patients as most important, then there will indeed be a difference between patient expectation and experience of dying.

There are few if any mechanisms through which patients are invited to discuss end-of-life care with a physician in enough detail and length to address their beliefs and values around death and how one should die. Discussions of Living Wills in this research revealed that these documents, a common precursor for physician-patient discussion of end-

of-life issues, are often not understood or remembered by patients. Not all of the participants who had Living Wills (n=13) indicated a clear understanding or intent for this document. Instead, it became clear that participants had confronted these forms only because hospital policy required that they be offered. Participants had not necessarily sought them out independently in an effort to plan for their own end-of-life and death. The self-report of a Living Will, then, did not necessarily indicate forethought or planning on the part of the participant. And the absence of a Living Will does not indicate lack of forethought. In competent patients, as Harty-Golder asserts that "nearly every study indicates that patients are quite capable of expressing their wishes, wish to do so, and expect their physicians to initiate conversation about end-of-life issues" (23:272).

Twelve participants stated they had a Living Will.

> MK: It's protection, so that nobody violates my rights theoretically... or the patient hasn't been coherent enough. The family sits there and says save him, save him.

Of the remaining six, only two could clearly describe the purpose of a Living Will and explain specific reasons for not wanting one. Others, including two persons who had signed a Living Will, confused it with a Will And Testament like this 79 year-old woman:

> CMS: How do you think that Living Will is going to help you? What's it's purpose?
> EB: Well I think whatever I have, it'll be designated to the people....
> CMS: Okay, that's the Will and Testament. Do you have, have you heard of a Living Will?
> EB: Oh yea, where I don't want to be resuscitated?
> CMS: Yes, how do you think that's going to work?
> EB: Well, I don't know. If I fall down dead, I certainly don't want all those machines put on me. I don't want that to happen to me. Just let me go.

DISCUSSION

Participants in this study disagreed on the type and amount of incapacity that would be intolerable or undesirable. Many, due to the sampling method, expressed an intention to commit suicide before suffering under what they considered intolerable health conditions. But consistently, participants defined their vitality, their alive-ness, in terms of their capacity to do, think, and act for themselves within the context of their life experiences and relationships. These definitions differ significantly from biomedicine's focus on physiologic function.

Where (professional) biomedical and patient ideologies collide is at the site of practice. The interactions between patient and physicians, especially but not necessarily on the subject of death and end-of-life care, display meaningful tension. The participants in this research attribute that tension to the manner and availability of the physician. When examinations are short and conversations are minimal, participants do not feel free to discuss all of their symptoms, questions, and problems (35). End-of-life issues are thereby given very short shrift and are often not understood or prepared for by patients. Approaching death raises difficult questions related to capacity and the cost-effectiveness of continued treatment; questions that patients cannot answer by themselves for lack of technical information.

The use of the Living Will clearly addresses some end-of-life topics that require attention. Concerns about resuscitation, life support equipment, and mental and physical capacity are among the most common in patients approaching death. However, these conditions are often present in only the final days of life, or under other catastrophic circumstances. Indeed:

> Because the biomedical location of ethical issues draws attention away from the mundane worlds of suffering where most illnesses are enacted and most treatments are undergone, voice is denied to the vast majority of health problems and outcomes. The extreme is emphasized over the routine" (3:51).

Neither the Living Will nor Do-Not-Resuscitate Orders provide any guidance for patients on the slow degeneration of aging and death. Biomedical practices around and in preparation for death, therefore, often neglect to prepare patients for the most likely scenarios of aging and death during this period of history. Instead, physician conversations and focus continues to be on treatment of treatable conditions; what the physician can do. From this, patients learn that biomedicine does not offer end-of-life care or preparation but symptom management.

The findings of my research thus show that the wishes people verbalize about end-of-life health care and what they can envision happening to themselves are different.[6] In sum, participants conceptualize, hope for, and plan for a dying process that is relatively unlikely, even when they are members of an organization founded on the notion of an informed, prepared death. Because end-of-life deterioration and disease are rarely acknowledged by patients as a process of dying, many elderly and dying patients seek treatment for chronic symptoms and terminal illnesses just as they have throughout their lives. In some,

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[6] These findings are similar to those of Emanual (34) and Knaus (19).

and of course not all, cases, this treatment seeking behavior contradicts what patients verbalize about how they expect and/or want to die. Although many verbalized an aversion to living life beyond physical and mental decline, they regularly discussed behaviors and intentions to treat symptoms. Only when catastrophic decline was considered did they say "pull the plug". This points to a systemic dilemma since so many chronic conditions are a *slow* progression of worsening symptoms.

Physicians, despite a broader understanding of epidemiology and degenerative process, contribute to and perpetuate this mind-set whenever they neglect to couch discussions of treatment and illness within a broader life perspective. Indeed, as discussed earlier, the approaching death of a patient is acknowledged only when biomedicine can provide no further intervention, that is, when the treatment is "futile". The period and processes before this moment are not conceptualized as a preparation for death but as a symptomatic period during which intensive medical intervention is still appropriate. In sum, death is conceptualized as a discrete moment, rather than a process of deterioration; dying is a diagnostic dilemma, rather than an experienced process over time.

CONCLUSION

Participants in the research expressed hope that their end-of-life decisions would be easy and clear, and that their death would be quick, painless, and without a period of incapacity preceding it. With a few noted exceptions, participants were reluctant to begin a discussion with their physicians about death. Even most Hemlock Society members had spoken little with doctors about the details of deteriorating capacity and the future need for care. Instead, when conversations about death had occurred, they had been largely limited to the scenarios of catastrophic illness (e.g., hospital-bound, "hooked up" to machines, etc.) and the Living Will.

Biomedicine's protocols, such as the completion of a Living Will or Do Not Resuscitate Order, address a minimum of end-of-life care issues. In the worst, although not uncommon, cases, these documents are poorly understood by patients and structure the dialogue between physicians and patients in such a way as to preempt other considerations of the dying process. If physician-patient dialogue is limited only to Living Wills and definitions of futility, what opportunity will patients have to develop a more complete view of or plan for their own death: one that reflects their cultural and historical personhood and worldview? If biomedicine is to improve the process of degeneration and death for its patients, then attention to processes of learning and meaning negotiation is crucial. The

discussion of the Living Will is one such process of learning and meaning negotiation in which the goals of the physician very frequently diverge from the goals of the patient. The narratives provided by the participants in this study revealed that biomedical practices to help patients discuss and plan for death do not meet patient needs or concerns in preparing for death. Instead, the Living Will and physicians' practices which limit dialogue on the topics of death and dying contribute to a power vacuum in which patients, for lack of information, are unable to act in their own best interests.

The important recommendation, one which is already being made in some of the clinical literature, is for biomedical practice to recognize that patients need opportunities to talk about death and dying. The purpose of this talk is not to collect a specific plan of action or designated responsible parties, as with the Living Will and Power of Attorney forms, but to allow patients to give verbal recognition to the issues and questions surrounding death and the dying process. The physician's role, contrary to the medical attorney's role, is to facilitate this part of the patient's preparedness and planning - not by directing the process, but by inviting it to begin.

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