

The Quest To Die With Dignity

An analysis of Americans' values, opinions and attitudes concerning end-of-life care.

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Introduction

Americans are more afraid of how they may die in today's health care system than they are of death itself. In a new study by American Health Decisions, funded by The Robert Wood Johnson Foundation, Americans discuss their views on health care at the end of life. Based on in-depth focus group discussions involving 385 Americans in thirty-two cities as well as two sets of follow-up interviews, *The Quest to Die with Dignity* identifies how Americans think about death and dying, how they want to be treated, and how they view planning documents such as living wills.

This report offers a new perspective by describing the opinions of randomly-recruited Americans, people who are not necessarily sick or dying or experienced with the health care system, and providing insights into how the broader public feels about health care at the end of life. In addition, follow-up interviews were conducted with Americans who are terminally ill or who have experienced the recent death of a loved one, in order to contrast their experiences and opinions with those of the focus group participants.

This report also explores how ethnic background, religious belief, and age may affect how Americans think about death and dying. When Americans who have different experiences and diverse backgrounds gather to discuss death and dying, they learn from each other, and their opinions evolve and change. The conclusions they ultimately draw are strikingly similar.

Americans participating in this study share similar, clearly articulated concerns, hopes and beliefs about the process of dying in America today. These include:

- They fear reaching the end of their lives hooked up to machines. They prefer a natural death in familiar surroundings with loved ones
- They do not believe that the current health care system supports their ideal concept of dying.

Although these Americans think it is important to plan for death and dying, they are uncomfortable with the topic and resist taking action.

They say family consideration is their primary concern in making end-of-life decisions.

The current planning options do not support the way these Americans want to manage the death and dying experience.

Listening To Americans

The Quest to Die with Dignity offers suggestions for addressing Americans' concerns about end-of-life care and indicates that fundamental changes are needed in how we plan for the end of life and how we care for the dying. It also provides ideas for furthering the discussion on death and dying in America, an important first step if more Americans are to begin planning for their end-of-life care. A hopeful sign is that Americans in this research hold much in common on this topic: they share the same concerns and fears, and they agree on the kinds of changes they want for improving end-of-life care. This consensus provides a strong foundation for those working to improve care for the dying.

A System Driven by Cost

These Americans believe the health care system is designed to cure illness and sustain life, not necessarily to help patients die the way they wish. Participants say the emphasis on curing even when death is inevitable can ironically result in treatments that prolong life "unnaturally" and cause unnecessary suffering. Many also believe that managed care and HMOs are negatively affecting health care and that cost, rather than what is best for the patient, determines the treatments they receive. Many research participants believe the relentless pursuit of profit drives health care decisions at the end of life and can even determine how long particular treatments are pursued and where patients will spend their final days.

The Doctor-Patient Relationship-A Crisis of Trust

Many research participants say they no longer feel close to their doctors. Some explain they often must leave doctors they trust when their companies switch health plans. Others say they see a different doctor every time they visit their doctors' offices. Most complain of being rushed through appointments. The result: a loss of trust in doctors. This lack of trust may explain why so many participants initially resist a role for doctors in helping them plan for the end of their lives and why they would question the motives of a doctor who suggested that they complete a living will. Research participants value doctors in the

traditional role of treating their illnesses and providing care when they are dying, but they initially reject doctors helping them plan for their end-of-life care.

Participants' views on doctors evolve, however, as they talk further. In fact, most participants (83%) indicated in follow-up interviews that, as a result of the focus group discussions, they would feel comfortable if their doctors initiated a conversation about end-of-life planning. Two factors may explain this change of heart: a growing awareness of the complexity of end-of-life decisions and a new appreciation for the importance of end-of-life planning in their lives. Still, they set conditions for doctor-initiated conversations about end-of-life planning. They say that doctors should only raise this topic during an annual check-up and not during a sick visit or when a patient is concerned about his or her health. They want the conversation to take place in the context of a long-standing and trusting relationship between the doctor and patient and, most important, when the doctor is willing to spend the necessary time to answer questions not rushing them through in five minutes.

Fear Of Being A Burden

Recurrent themes in the focus groups are the importance of remaining independent and self-sufficient coupled with the deep fear of burdening one's family when dying. These Americans do not want their dying to burden their families financially, emotionally, or physically, and so, would weight these factors heavily when making decisions about their end-of-life care. This could include forgoing expensive treatments or perhaps "pulling the plug" rather than languishing unconscious in a hospital. Research participants express their willingness to make sacrifices to spare their loved ones. Interestingly, their perspectives reverse when they talk about loved ones who are dying. In such cases, they admit they are willing to "spend their last dollar" and "go to the ends of the earth" to keep their loved ones alive.

Dying - I'd Rather Not Discuss It

Research participants create long lists of reasons why they avoid talking about death and dying. They say it is "sad," "depressing," "bad luck," or "too far in the future." They say they are too busy living to focus on dying. Even those participants who want to talk about death say their loved ones resist having this conversation because it is depressing. These Americans seem to believe that vague comments about "not wanting to be hooked up to machines" are enough that they do not need to have more explicit conversations to guide their loved ones in making complex and emotional decisions about their end-of-life care. This research suggests that until Americans are more comfortable talking about their deaths, they are unlikely to take the most preliminary steps to plan for their end-of-life care.

The lack of a common language to talk about dying is a significant barrier to planning. Most research participants are simply unfamiliar with terms like "advance directives," "life-sustaining treatment," and "futile treatment." Even terms that are familiar, such as "living wills" and "hospice," are often misunderstood. To research participants, these terms imply financial planning and the creation of wills to disperse their belongings, not planning for end-of-life care. The words used by the health system, doctors, attorneys, and other experts to talk about the dying process do not register with most Americans.

Advance Directives-One Size Cannot Fit All

Research participants are skeptical of the current tools for planning their end-of-life care and see documents like living wills as inadequate. While these Americans insist that the patient's wishes should always drive treatment decisions, an important theme throughout this research, they do not see current advance directives as the answer. Some argue that today's advance directives are too narrow and cannot address the range of decisions that may have to be made when they are dying. Others worry that such a rigid document will lock them into an irreversible course of action, possibly removing them from life-support equipment too soon. Time is an important factor to research participants, who do not want the decision to "pull the plug" rushed or made when a patient's prognosis remains unclear. Even those participants who are not concerned about the documents themselves doubt that family members or doctors will pay attention to their living wills. Finally, many research participants appear to lack a basic understanding of advance directives and most do not know how to obtain these documents or complete them. They believe that they need to talk with an attorney first and that the process for completing an advance directive is expensive.

Beyond these basic concerns, participants initially question whether a written document is even necessary. They argue that their loved ones already know what they would want, so why write it down? They believe their loved ones intuitively know what to do and will make the right decision, whether it is to "pull the plug" or to continue life support. It is only when participants hear the emotional testimonials of those who have had to make such difficult decisions that these Americans say that it is "unfair" to burden others with their life-and-death decisions without having given them an indication of what they would want. Thus, the most persuasive argument for Americans to complete an advance directive is that it can relieve family members of the burden of making agonizing decisions and of the guilt they believe would follow such decisions.

Dying Well

Research participants fear dying while hooked up to machines, suffering and lacking control

over what happens to them. While they appreciate the short-term benefits of life-support equipment when recovery is a realistic possibility, they see this same equipment as an enemy when it is used for prolonged periods and in cases where recovery is unlikely. They believe the latter scenario using life-support equipment to prolong life unnaturally happens frequently, and they fear this will be their fate. They fear even more that they will die in pain. Many participants say with anger that they have witnessed loved ones suffer in hospitals. They do not accept that concerns about addiction should prevent some health care providers from giving adequate pain medication. Likewise, they do not want providers to hold back on pain medication because it may, as a side effect, hasten death. Dying well, for most of these Americans, means dying pain-free, relieved from all suffering. For many, it means dying at home, surrounded by loved ones, and untethered to machines.

Deep Divisions on Physician-Assisted Suicide

Research participants are deeply torn about physician-assisted suicide and discuss the issue from a range of perspectives. Those who support it seem driven by a sense of compassion for suffering patients. Many see physician-assisted suicide as a humane alternative to prolonged pain and suffering and make comparisons to the merciful ways in which dying animals are put to sleep. A number of research participants also argue that it is the "ultimate individual right" for dying people to choose the time and manner in which they die, not something for a judge or the legal system to dictate. While many participants say they would not choose physician-assisted suicide for themselves, they would not take away someone else's right to make that choice. But these Americans also worry about abuses if physician-assisted suicide is permitted for example, that patients may make decisions when they are depressed or in a confused state of mind or that such a decision would be made for someone on the basis of cost or convenience. Some participants also say they oppose physician-assisted suicide because of religious beliefs and a feeling that it is simply wrong to take a life.

GROUP DIFFERENCES

To a remarkable degree, the different groups of Americans participating in this research share the same opinions, values, and concerns about death and dying. Across the thirty-six focus groups, Americans from diverse backgrounds say they want the same thing: a humane, compassionate process for dying that allows them as much control as possible over what happens at the end of their lives. When they talk about end-of life care, most agree that they want basic human rights. They differ only on a few specific issues in which ethnic and cultural background, religious beliefs, and age and experience seem to shape their perspectives. While it was neither the focus nor the intent of this study to define the belief systems of these distinct populations with regard to end-of-life care, some broad

observations can be made about perceptible differences among the groups.

Ethnic background accounts for the greatest differences among research participants. In comparing the responses of participants within the various ethnic groups, these differences emerge:

- African American and Native American participants are most reluctant to support either physician-assisted suicide or age as a factor in making treatment decisions for the terminally ill.
- White and Asian participants are more likely to place trust in the health care system and indicate a greater willingness to terminate life support than do Native American, African American and Hispanic participants.
- African American participants are more likely to indicate that a lesser quality of life would be acceptable to them as long as their lives were saved.

Religious beliefs do not appear to influence participants' opinions as much as ethnic background. However, participants' responses do suggest the following:

- Muslims are less trusting and are more critical of the American health care system than other religious groups because they seek more sensitivity to their religious/cultural needs.
- Jewish participants are more likely to support physician-assisted suicide. Protestant and Catholic participants are equally split on the issue of physician-assisted suicide

Age seems to have even less bearing than ethnic background or religious beliefs on attitudes toward end-of-life care. However, the responses from those participants between 18 and 34 are most unlike those of the other age groups, showing more distrust of the health care system and more support of physician-assisted suicide.

MOVING FORWARD

Ten key suggestions for improving the process of dying emerge from the research discussions. These ideas offer broad directions for change rather than policy proposals that can be implemented quickly. The suggestions offered here should be seen as a starting point for dialogue. They point to the need for changes in the delivery of health care, in the treatment of dying patients, and in the relationships between providers and patients. There are clear implications for doctors' roles and responsibilities when it comes to end-of-life care. These suggestions also call for patients to assume greater responsibility for their own care, to learn more about treatment options, and to take the initiative in planning for end-

of-life care. Finally, they suggest that we, as a society, must change to become more comfortable talking about and dealing with death and dying. Ten suggestions for improving end-of-life care are:

1. Create public dialogue to motivate more Americans to plan for their end-of-life care. To be successful, this type of dialogue will require a strategy for overcoming Americans' aversion to talking about death and dying. However, this research suggests there is cause for optimism. Once research participants engage in conversations about end-of-life issues, they begin to see the value of planning and may be able to overcome their resistance to completing advance directives.
2. Address the language gap that exists between experts and the public when it comes to end-of-life issues. Patients, doctors, attorneys, the media and others need to use the same terminology to talk about care for the dying and the end-of-life planning process.
3. Re-establish doctor-patient relationships so that patients are comfortable seeking their doctors' advice on end-of-life issues. This study shows that there has been a loss of trust in doctors among research participants and that doctors are not initially considered to have a role in end-of-life planning. Nurturing long-term relationships between doctors and patients is a critical step if patients are to allow doctors a more central role in helping them plan for death.
4. Provide information to enable patients to take more responsibility and make informed decisions about their health care at the end of life. Participants indicated that they want to know all of their treatment options, their odds for recovery, alternative treatments, and what to expect when dying so that they can make informed decisions about their care.
5. Develop a different type of end-of-life document that is broad enough to address the range of options that Americans may face when dying. Americans want a flexible document, one that is easy to update, and one that enables them to include more information than when to "pull the plug." Additionally, if more Americans are to complete advance directives, they must have assurances that doctors will honor them.
6. Overcome barriers to adequate pain management so that providers' concerns about addiction or hastening death do not interfere with their ability to relieve suffering. Americans fear they will die in pain and need to hear from providers that relieving pain is a guiding principle in care at the end of life.
7. Expand hospice-type services so that Americans can have more options about where they die. Participants acknowledge they need skilled medical help and other assistance to care for a dying loved one at home. Adequate insurance coverage

should exist so that Americans have the supports they need to care for their loved ones at the end of life.

8. Recognize patients' wishes as expressed by family members, those whom patients trust most to make end-of-life decisions for them. Most Americans do not have written advance directives and want the instructions they have given to their loved ones to guide their care. Doctors and other caregivers should work closely with family members to understand oral communications about the type of care the patient wants at the end of life.
9. Consider using incentives like lower insurance premiums to motivate more Americans to put their wishes into writing and to complete advance directives. However, efforts to encourage Americans to complete advance directives must be pursued carefully so that the motives of doctors and others are not misunderstood.
10. Respect cultural and religious differences to ensure that important values and practices surrounding death and dying are honored. Some Americans from diverse backgrounds express frustration that the current system is insensitive to their cultural and religious beliefs and want to know that their norms will be respected during the difficult time of death

METHODOLOGY

A total of 385 randomly-recruited Americans participated in thirty-six focus groups, facilitated by professional moderators and conducted between March and May, 1997. Focus groups lasted two and one-half hours and were audio taped. The audio tapes were transcribed for later content analysis.

A two-tiered approach to the focus groups was taken . The first tier consisted of twelve focus groups with a demographic cross-section of Americans. Each focus group included a mix of individuals from various income and education levels, gender, age groups, and religious and ethnic backgrounds. These focus groups gave insight into how Americans from various backgrounds talk together about end-of-life issues.

The second tier consisted of twenty-four focus groups with individuals of like ethnic, age, or religious affiliation. These groups were divided as follows:

Ethnic Groups Age Groups Religious Groups

African American	18-34	Protestant
Hispanic	35-54	Catholic
Asian	55-64	Jewish
Native American	65+	Muslim

The rationale for the two-tiered approach was to ensure that the voices of Americans who might have distinct attitudes and experiences on end-of-life issues were heard in this research. Additionally, a relational database was developed to allow researchers to quantify the data and further explore similarities and differences.

In addition to the focus groups, twenty-nine in-depth interviews were conducted with nine terminally ill persons and twenty family members who had experienced the recent death of a loved one. Interviews were audio taped and later analyzed to compare themes with those emerging from the focus groups conducted with randomly-recruited Americans. Additionally, follow-up interviews were conducted with sixty-five individuals randomly selected from the focus groups to explore how participating in the focus group discussions affected the behavior of these individuals in terms of planning for their end-of-life care.

Focus group research is qualitative and, as such, should not be considered representative of how all Americans feel about end-of-life care. Focus groups are most useful in revealing possible trends, in uncovering underlying motivations and perceptions, and in bringing to light the values, beliefs, and emotions that shape opinions on issues.

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