

REFLECTIONS OF THE TIMES

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The Right To Die

Americans, by a wide six to one majority, support the right of patients to make their own decisions about receiving life-sustaining treatment. The public also overwhelmingly thinks that close family members should be allowed to make decisions about life-sustaining medical treatment, if the patient is unable to make his or her own wishes known. All segments of the public, including members of all major religious groups, support right-to-die policies. This support stems from the widely-held belief that physicians should sometimes allow a patient to die, rather than use the full range of medical procedures and treatments available.

The views that Americans' express about right-to-die *policies* reflect their feelings about how they would want their *own* medical treatment to be handled, and what they can imagine about the wishes of their parents in such painful or debilitating circumstances. Most Americans would want life-sustaining treatment withdrawn if they were suffering a great deal of pain from a terminal disease, or if they became totally dependent on another person for daily care.

Underlying the public's attitudes on the right-to-die and patient choice is a recent trend toward greater acceptance of suicide in the face of suffering from a terminal disease.

These are among the findings of a new *Reflections of the Times* poll of 1,213 adults nationwide. The poll, conducted for the Times Mirror Center for the People and the Press in Washington, D.C., examined in-depth the public's views about dealing with terminal illness and disability.

Right to Die Policies

Eight in ten Americans think there are sometimes circumstances where a patient should be allowed to die, whereas only 15 percent think doctors and nurses should *always* do everything possible to save the life of a patient. Non-whites, born again Christians, people who are very religious, and people over age 65 are slightly more likely to think that a patient's life should always be saved. However, even among these groups a clear majority believes that, in some circumstances, a patient should *not* receive life-sustaining treatment.

The public's feelings about right-to-die legislation is driven by its belief in the need for discretion in administering life-sustaining medical treatment. Eight in ten adults approve of state laws that allow medical treatment for a terminally ill patient to be withdrawn or withheld, if that is what the patient wishes. Only 13 percent of the public disapproves of laws that let patients decide about being kept alive through medical treatment, and five percent approves of these laws only in certain situations. Again, non-whites, people age 65 and older and people who are very religious are less likely to express approval for right-to-die legislation. However, no less than a seven in ten majority in all population subgroups approves of right-to-die legislation in at least some circumstances.

Most states have some form of right-to-die legislation, but the issue remains controversial. For the first time in its history, the U. S. Supreme Court is now considering whether there is a constitutional right to discontinue life-sustaining medical treatment in the case of **Cruzan v. Harmon**. In New Jersey, right-to-die legislation recently approved by the state Senate is drawing criticism from several members of the State Bioethics Commission that produced the proposal for the legislation, and from some religious and right-to-life groups in the state. It's uncertain whether the bill, approved last month by the New Jersey Senate, will be approved by the Assembly and signed into law by Governor Florio.

Less than half of the states that have enacted right-to-die legislation to date have also included provisions for patients to specify a health care spokesperson, or proxy, to authorize withholding or withdrawal of their life support. However, the public clearly supports the use of proxy decision-makers.

In the view of most Americans, close family members ought to be able to serve as proxies for terminal patients who are unable to communicate and have not made their wishes known in advance. Seven in ten think family members should be allowed to make decisions about medical treatment on behalf of the patient, while another five percent think this is appropriate only in some circumstances. Only about one in six adults overall, and a slightly greater proportion of non-whites, think such proxy decision-making should *not* be allowed. People over the age of 50 express somewhat more uncertainty, with just under one in five unsure about whether proxy decision-making should always be allowed.

The public, in particular those with strong religious feelings, makes an important distinction between how decisions about medical treatment should be made for adults and how they should be made for infants. Half of the public *rejects* the notion that parents can refuse life-sustaining treatment on behalf of their severely handicapped infant, asserting instead that such infants should receive as much treatment as possible. A third accepts the idea that parents should be able to refuse medical treatment for their severely handicapped infant, while eight percent would agree only under certain circumstances.

The public's distinct ideas about right-to-die issues with respect to infants are not motivated by a general rejection of "proxy" decision-making, since the overwhelming majority favors letting close relatives make treatment decisions where the patient is unable to express his or her wishes. Experts point to several other reasons that opinion about infant patients differs from opinion about adult patients.

Susan M. Wolf is a lawyer with The Hastings Center, a research institute in New York that studies medical ethics. She notes that medical decision-making for handicapped infants has become quite different than that for adults because "it's difficult to agree on what the patient's best interests are in the case of a newborn and there's no way to extrapolate what the patient would want from knowledge of his or her life." She also remarks that cases of decision-making involving infants have been influenced by the direct involvement of the federal government in passing legislation that recognizes withholding life-sustaining medical treatment as a new category of child abuse.

Religion profoundly affects views about the proper treatment of severely handicapped infants, with born again Christians and those who are very religious most opposed to parental decision-making in these cases. In fact, majority support for the right of parents to refuse medical treatment *only* occurs among those who say religion is *un*important in their lives (51%). Whites, women and adults age 30 and older are also more likely to favor the rights of parents to decide about medical treatment.

There is no difference, however, in the views of Protestants and Catholics about parental decision-making. In fact, in *all* areas of this investigation, Protestants and Catholics disclose similar opinions. It is the *relevance* of religion to a person's day-to-day life that affects opinion on right-to-die issues, rather than one's adherence to a specific set of religious *beliefs*.

The Implementation of Patient Wishes

One of the features of the New Jersey legislation grants immunity from civil, criminal and professional liability to physicians who carry out their patients' instructions for treatment. Many states have such legislative provisions. Yet, many observers have noted that physicians often do not carry out their patients' wishes with regard to life-sustaining medical treatment because they lack such explicit legislative protection and because they have an inherent tendency to seek *treatment* solutions for their patients' conditions.

A special panel of a dozen physicians, writing last year in *The New England Journal of Medicine*, noted that a patient's written instructions, or directives, regarding treatment "do not exert enough influence on either the patient's ability to control medical decision making at the end of life or the physician's behavior with respect to such issues in hospitals, emergency rooms, and nursing homes. There remains a considerable gap between the acceptance of the directive and its implementation."

In fact, few people think doctors and nurses pay a lot of attention to instructions from patients about whether they want treatment to keep them alive. Only one in five (20%) say that medical professionals pay a lot of attention to patients' wishes, although this view is slightly more prevalent (28%) among people who actually have helped to make medical treatment decisions for a loved one who suffered a prolonged or painful death. For the public as a whole, 37 percent think medical professionals pay "some" attention to patient wishes, 28 percent think little or no attention is paid, and 15 percent have no view about how medical professionals consider patient wishes in making treatment decisions.

Americans are split in their opinions about how cases where patient wishes have been ignored should be handled. Asked to consider a situation where a patient does not want treatment to be kept alive, but receives it nonetheless and survives in a severely disabled condition, four in ten (42%) think the doctor or hospital should be held *legally* responsible for the patient's disabled condition. However, almost as many (35%) think the hospital staff is justified in trying to save the patient's life.

Suicide and Mercy Killing

Most Americans are willing to go much further than simply supporting right-to-die policies when considering cases of *adults* who are suffering with a terminal disease or disability. Seven in ten adults think it is justified at least some of the time for a person to kill his or her spouse, if the spouse is suffering terrible pain from a terminal illness. Only one in five thinks this is never justified.

About half of the public thinks a person has a moral right to commit suicide if suffering from an incurable disease or suffering great pain with no hope of improvement. Acceptance of suicide in such cases has been increasing gradually over the fifteen year period since 1975 when these attitudes were first measured by the Gallup Poll. Forty-nine percent of the public now thinks a moral right to suicide exists if a person has an incurable disease, compared to forty percent in 1975. Over half (55%) now thinks a person suffering great pain with no hope of improvement has a moral right to suicide, compared to only four in ten (41%) fifteen years ago.

The increasing acceptance of suicide is largely due to the aging of the population. The older people who overwhelmingly rejected suicide as a response to terminal illness 15 years ago have died and been replaced in the population by younger people with more moderate views about the acceptability of suicide in these circumstances.

Attitudes toward suicide remain patterned by age today, with more acceptance of suicide expressed by younger people in the cases of incurable disease or great suffering. For example, two-thirds (67%) of adults under age 30 and 58 percent of those age 30 to 49 think a person has a moral right to suicide if suffering great pain from a disease with no hope of improvement. Fewer older people agree-- just under half (47%) of those age 50 to 64 and 39% those 65 and older.

The public makes clear distinctions about the acceptability of suicide between cases involving terminal disease and suffering, as opposed to those where the patient has become a burden on his or her family, or daily life has become a burden to the patient. Majorities of Americans *reject* a moral right to suicide, with 57 percent opposed if the burden on the family is extremely heavy and 59 percent opposed if life is a burden for the individual. However, even these attitudes represent an increase in acceptance of suicide over 15 years ago, when almost three in four (72%) Americans rejected a right to suicide in cases where a patient has become an extremely heavy burden on his or her family.

Religion plays a key role in determining views about ending the life of a suffering person through these more extreme non-medical means. Attitudes about suicide and killing a spouse differ *greatly* depending on the strength of one's religious views, although differences by degree of religious commitment are slight on most other aspects of right-to-die policy.

Most born again Christians and very religious people reject a right to suicide even in the case of a terminal illness, and are fairly evenly divided in their attitudes about suicide when the patient is suffering great pain. Yet, paradoxically, a majority of born again Christians and the very religious think acts of so-called "mercy killing" by spouses are sometimes justified.

It appears that some Americans, particularly those who are very religious, make an important distinction between what is "justified" and what is a "right." This implies that the difficult decision to end a person's life is perhaps justified, understandable, and acceptable, yet not *endorsed*.

Personal Wishes

The views that Americans' express about right-to-die policies reflect their personal feelings about how they would want their own medical treatment handled in various situations, and what they know or can imagine about the wishes of their parents. People's feelings about whether they would choose to receive or continue life-sustaining medical treatment change depending on the medical circumstances of the case.

More than half of Americans would want their doctors to stop administering life-sustaining treatment if they had a terminal disease and were suffering a great deal of physical pain (59%), or if they had an illness that made them totally dependent on another family member for all daily care (51%). Less than a third are certain of their desire to have their physicians pursue every possible treatment in these two situations (28% and 31%, respectively).

Over four in ten (44%) would want medical treatment stopped even in the case where a terminal disease made it difficult to function in day-to-day activities, whereas 40 percent would want all possible life saving medical treatments and procedures used.

Personal choices about medical treatment in these three situations are shaped by the importance of religion in one's life. In all cases, the wish to have life-sustaining medical treatment withdrawn decreases as the importance of religion increases. However, a majority (52%) of even the very religious would want their own treatment stopped if they were suffering a great deal of physical pain.

Personal choices also vary by race, with non-whites less often thinking they would opt to have treatment stopped, and choices vary by age. Young adults, under age 30, do not make distinctions about how they would want their own treatment handled depending on the nature of the situation, while older adults make such distinctions. For example, more people over the age of 65 would want their treatment stopped if they were suffering great pain (60%) than if they were dependent on a family member (49%) or had difficulty with daily living (47%). Young adults do not distinguish among these situations in judging how they would react (49%, 50% and 44% would want treatment stopped in these three situations, respectively).

Most people think their parents' wishes for medical treatment in these circumstances are similar to their own wishes. About half of those with living parents think their mothers and fathers would want medical treatment stopped if they were suffering a great deal of pain in a terminal disease (54% for mothers and 50% for fathers), or if they became totally dependent on a family member (49% for mothers and 48% for fathers). Four in ten think their parents would want medical treatment stopped if daily activities became a burden (43% for mothers and 42% for fathers).

Although religion plays a role in shaping an individual's *own* wishes about medical treatment, it does *not* influence perceptions about the amount of treatment one's parents would wish. There are few differences in perceptions about fathers' wishes that relate to characteristics of the people interviewed for this study. However, there are important group differences in perceptions of mothers' wishes.

Daughters' and sons' perceptions of their mothers' wishes for medical treatment are different, as are the perceptions of those whose mother is under age 60 and those with an older mother. Daughters are more likely than sons to think that their mothers would want treatment stopped in all three situations considered. Those whose mother is over the age of 60 are more likely to think their mother would want treatment stopped if she was suffering great pain.

In large part, these differences arise because daughters are more likely than sons to have explicitly *discussed* a mother's wishes with her, and because these discussions are more frequent between mothers and their children when the mother is older. Often, mother and child have together experienced the death of the child's father, where these medical treatment issues may have become relevant. In fact, people who have participated in medical treatment decisions for a loved one (15 percent of American adults have been involved in this kind of decision-making) are more likely to think their mother would want her own medical treatment stopped, especially in the case where she becomes totally dependent for her care on another family member.

Over four in ten (43%) adults have talked to their mothers about her wishes for medical treatment, including 37 percent of men, almost half (49%) of women, over half (58%) of those whose mother is 70 or older, and two-thirds (68%) of people who have participated in medical treatment decisions for a deceased loved one. Fewer adults (28%) have had such discussions with their fathers. Almost one in six (16%) people are aware of written instructions that exist for their mother and 16 percent also know that their father has written instructions regarding his wishes for medical treatment.

A third of adults can imagine *themselves* taking the life of a loved one who was suffering terribly from an illness that was terminal (28% can imagine this unequivocally and 5% can only imagine it under certain circumstances). Almost six in ten (59%) cannot imagine such an action and 8 percent are unsure. The ability to imagine the mercy killing of a spouse or other loved one is greater for men, and it decreases significantly with age, presumably as the possibility of actually facing such a choice becomes more likely. For example, four in ten (40%) young adults (under age 30) can imagine a mercy killing under some circumstances, compared with only half as many (20%) people age 65 and older.

Strength of religious feeling also affects how people imagine their own behavior if their husband or wife was suffering great pain from a terminal disease. Those for whom religion is very important are much less likely than others to be able to imagine taking the life of a loved one who is suffering (25% if religion is very important, compared with 40% if religion is somewhat important and 52% if religion is not important).

Half the married people (51%) have talked to their spouse about his or her wishes for medical treatment and one in ten (11%) spouses have written instructions regarding these wishes. Non-whites are much less likely than whites to have had such discussions, whether with their husband or wife, mother or father.

Americans, particularly older Americans, have thought about their own wishes for life-sustaining medical treatment. Almost three in ten (28%) say they had already given these issues a great deal of thought before they were interviewed for this study, 36 percent had given some thought, 22 percent not very much thought, and only 13 percent had given no thought at all to decisions about medical treatment in these severe cases.

Over a third (35%) of those age 50 or older has given a great deal of thought to their own wishes for medical treatment. Most strikingly, half (47%) of the people with direct experience of the difficulty of making treatment decisions for a dying loved one have given careful consideration of how they would want their own situation handled.

Almost two-thirds (64%) of the people who have considered these issues have also discussed their feelings about medical treatment with a spouse (34%), child (15%), parent (15%), other relative (14%), medical or legal professional (5%), or with another person (10%). Women and people in affluent households (\$50,000 or more in annual income) are more likely to have had these conversations than men and less affluent individuals. Women average slightly more conversations than men, and women more often discuss these issues with a child. Age and experience with a painful or prolonged death are also related to having had conversations with others about wishes for medical treatment. And, almost three-fourths (72%) of the people who helped make treatment decisions for a dying loved one have talked to a family member, friend or professional about the treatment they would want for themselves.

A living will is a document that provides a patient's instructions to his or her doctor about when life-sustaining medical treatment should be withdrawn or withheld. Almost one in seven (14%) American adults has a living will or has put their wishes for medical treatment in cases of terminal disease or disability in writing, including almost one quarter (24%) of adults over age 64 and almost one quarter (24%) of those who have helped make medical treatment decisions for a loved one.

Seven in ten Americans (71%) have heard of living wills, with high awareness among college graduates (83%), affluent individuals (85%), and women (75%) and low awareness among young adults (56%) and non-whites (50%).

FEELINGS ABOUT AGING

In today's rapidly aging society, Americans have profoundly mixed feelings about growing old. Only four in ten (39%) adults would like to live to be 100 years old, and half (49%) would emphatically *not* want to live to be that old. Women, in particular, do not look forward to reaching the milestone of their 100th birthday, which is ironic, since this accomplishment is more likely for a woman than a man. Only 31 percent of women, compared with almost half (48%) of men, admit that they would like to be 100 years old.

Americans express a wide variety of feelings when they imagine what will face them in old age. But, the range of concerns and worries they articulate is far greater than the joys and rewards they expect. When asked in an unstructured way to talk about what they most look forward to about getting old, almost everyone (85%) can name something. Most people mention not having to work, or having less stress and pressure in their lives (54%). Some people mention other specific expectations like the joy of sharing in the lives of their children and grandchildren (14%), travel (7%) and experiencing broad social changes (3%). A few (2%) even say that they most look forward to death and eternal life with God. But, most focus their positive feelings about aging on the reduction of their responsibilities in the world.

When the public is asked about their greatest worries, a wide range of specific concerns about old age emerges. Three in ten (31%) mention worries about health, and another five percent name a specific disease that they fear. One quarter worry about what their financial situation will be like when they're old (24%). Over one in six (17%) fears having activities restricted or losing the ability to be independent, and another 4 percent worries about senility. Five percent, including 13 percent of those younger than 30 now, worries about death itself. Four percent worries about the

world situation. Optimistically, almost one in five (19%) of those 50 or older (compared with only 6 percent of younger adults) claims to worry about *nothing* when anticipating old age.

Methodology

This survey is based on telephone interviews with a representative sample of 1,213 adults, age 18 and older, living in the continental United States. Interviews were conducted during the period May 1 to May 5, 1990. For results based on the total sample, one can say with 95 percent confidence that the error attributable to sampling and other random effects is plus or minus three percentage points. In addition to sampling error, question wording and practical difficulties in conducting surveys can introduce error or bias into the findings of opinion.