The Will to Live

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ABSTRACT: Since the abortion decisions of 1973, there has been a change in medical ethics in which the "presumption for life" has been replaced by the "quality of life" ethic. A number of legislative and legal events have occurred in America that have brought about this major change in attitude and value regarding the right to life in medical decision-making. One of the results has been an increased use of euthanasia, especially for older persons and those with disabilities. The "Will to Live" is an advance directive that calls for a presumption in favor of life. It is designed to prevent patients from becoming victims of our growing "culture of death."

THE NATIONAL RIGHT TO LIFE COMMITTEE is best known for its opposition to abortion. It is less well-known to have always included opposition to euthanasia and infanticide as part of its mission. We hold this position because we believe that undermining the right to life at the beginning of life will inevitably lead to attacks on the right to life at the end of life and in cases of disability.

The strategies used by the National Right to Life Committee to fight against the increasing culture of death in America have changed over time, for our opponents have changed their approach to euthanasia. When the U.S. Supreme Court made abortion legal nation-wide in 1973 by its *Roe v. Wade* and *Doe v. Bolton* decisions, very few Americans favored euthanasia. Warnings by the pro-life community that legalizing abortion would lead to more favorable attitudes toward euthanasia largely fell on deaf ears because the value-system pertinent to healthcare that was prevalent at that time still valued the preservation of life so strongly that most people could never imagine widespread acceptance of euthanasia. But in the years since legal abortion became the law of the land in America, support for euthanasia has become so widespread that we can now fairly say that we are living in a "culture of death."

How did this happen? What factors caused this shift in attitudes? The fundamental value-system supporting our treatment of the sick and those with disabilities was the traditional one that was long at the core of our American way of life. It included the belief that every individual human life has unqualified dignity and value, regardless of one's age or condition of health or disability. It always involved a "presumption *for* life."

This belief was supported in medical ethics by the Hippocratic

Oath, which called upon doctors to "do no harm." Doctors were expected to provide life-saving medical treatment as well as food and fluids for their patients. Traditionally the courts also supported the ethical principles represented by this time-honored oath. The Hippocratic Oath also called upon doctors to avoid aiding in abortions. Once doctors began to violate one part of the Oath (the prohibition on abortion), other aspects proved easier to ignore. Today most doctors do not take the Hippocratic Oath.

In a few short decades these principles were replaced by "quality of life" judgments. As a result, the provision of medical treatment is being determined more and more by subjective assessments about the quality of a person's life. Gone from the discussion is the recognition of any inherent dignity. How can we tell when a medical judgment is being made on the basis of an assessment of the "quality" of the person's life? If denial of a particular treatment for an older or disabled patient would not be made for a younger, otherwise healthy person (presuming that the risks of the treatment are not disproportionate), then the judgment is being made based on age and/or disability. This constitutes euthanasia by omission.

Modern medical treatment has gradually become so sophisticated that people can be kept alive when they once would have died for lack of knowledge and skill. The pro-euthanasia forces have exploited the natural fears that people had that they might be "over-treated" by being kept alive in a way that would merely "prolong the dying process." Ironically, at just the time that most people had no reason to worry about "over-treatment," a push began by the pro-euthanasia forces to develop a fear in the public mind. The legal instrument called the "living will" was devised as a way in which to prevent certain kinds of treatment from being given to a dying patient. But living wills were actually unnecessary to prevent "over-treatment," both because the accepted standards of medical practice did not require such treatment and because the doctrine of informed consent enabled patients and their families to reject such treatment without resort to formal (written) advance directives.

Many people might say that they would not want "extraordinary treatment" if they were in a terminal condition. The problem, however, is that what seemed "extraordinary" years ago is now often ordinary in most parts of this country. What is presumably "extraordinary" treatment if one lives in an isolated, rural area is "ordinary" at a hightech, urban hospital. What would be "extraordinary" for an indigent patient can well be "ordinary" when backed by payment from a good healthcare plan. But what might appear to most people to be "ordinary care" might come under the category of "extraordinary care" from the viewpoint of a hospital system. Most people, for example, would

presumably assume that the provision of food and fluids is a matter of "ordinary care." But if an illness makes it difficult for individuals to feed themselves in the ordinary way and they require a feeding tube, the provision of food and fluids suddenly becomes "extraordinary care" under the legal policies governing hospital regulations, and especially in situations in which there are living wills in place.

Many pro-life groups, including the National Right to Life Committee, therefore opposed living-will legislation by pointing out the vagueness of the language typical of living wills, the way in which the seemingly harmless terms that they regularly use are open to a variety of interpretations that can expand the denial of treatment that they cover far beyond the intent of those who signed them. Pro-life groups also warned that the strategy of "right to die" groups was to use living wills to encourage public acceptance of assisted suicide, mercy killing, and euthanasia by replacing the then-accepted ethic that the lives of all human beings are of equal and inestimable dignity with the view that the value of human life depends on its "quality."

The pro-life movement lost the fight to prevent the enactment of living will legislation. Subsequently the vague language in most living will statues was gradually amended to clearly extend the range of their denial of life-saving procedures to more and more instances. The provision of food and water by such means as pegs and intravenous tubes was shifted from the status of ordinary care to the category of medical treatments. Denial of medical treatment was authorized not only for "terminal illness" (itself often very broadly defined) but also for "irreversible conditions" and other euphemisms that have come to be used for permanent disabilities. Most dangerous of all, court after court, and then state legislature after state legislature, adopted rules allowing the denial of medical treatment and even the provision of food and water to older people and people with disabilities who had never signed living wills nor otherwise rejected life-saving measures.

The involvement of the courts in this process is especially troubling because the courts should be protecting the Constitutional right to life of individuals, not undermining it. In the move toward the acceptance of euthanasia in America, one legal aspect of the debate involves ascertaining the degree of the patient's desire for euthanasia. Euthanasia may be voluntary (meaning that the patient, while competent, has requested it), non-voluntary (meaning that the patient's wishes are unknown, and that the courts or a surrogate impose it), or involuntary (meaning that death is chosen for the patient against his or his surrogate's explicit wishes).

In this area the courts have increasingly allowed a shift from voluntary to non-voluntary deprivation of life-saving medical treatments. The 1976 *Quinlan* case inaugurated the doctrine of

"substituted judgment" by which it was argued that an incompetent individual could not be deprived of the competent individual's right to reject medical treatment "merely" because she or he could not choose to do so. Rather, it was held that another party – the court, a family member, or a government bureaucrat – could step in and exercise that right on the incompetent person's behalf. Ignored was the individual's right to choose to accept treatment – to choose life.

Involuntary denial of treatment first came to have the force of law in 1992 when Virginia passed a statute explicitly authorizing a doctor to decide that to follow a patient's expressed desire for life would be "medically or ethically inappropriate." Fortunately, some years later, Virginia amended the law so as to give a patient at least a limited time to transfer to a more sympathetic healthcare provider before treatment is cut off. Other states have adopted a similar construction of the law.

A second legal aspect of the debate involves the question of the method by which euthanasia is to be considered legally acceptable. The first method involves simply denying the patient the necessary medical care. This is passive euthanasia. But, once the provision of food and water is determined to be "extraordinary care," it is possible to move from rejection of medical treatment to the rejection of food and water. California's *Bouvia* case was the first to authorize euthanasia by removal of food and water from a competent adult. But this decision simply opened the door to doing it under the doctrine of substituted judgment for non-competent and incompetent persons.

Direct killing was first legalized by a 1994 referendum in Oregon, whose assisted suicide law became effective in 1997, after withstanding a number of court challenges. A referendum in favor of allowing assisted suicide subsequently passed in the state of Washington. While these laws ostensibly legalize only voluntary killing, their lack of protections for patients combined with the evidence of the words of euthanasia advocates clearly indicate that the ultimate goal of the euthanasia proponents is to move to non-voluntary (and even involuntary) active euthanasia.

In summary, it is clear that there has been a major change in attitude and value regarding the right to life in America. This change has been codified into law through both the state legislatures and the courts. We cannot expect that our right to life will be respected when we become ill or disabled, which could happen at any time during our lives. The problem of non-voluntary passive euthanasia for those with disabilities received national attention with the case of Terri Schiavo.

Terri Schiavo was disabled and needed to be fed through a feeding tube in order to manage her care. She had been a perfectly healthy young woman before an unidentified medical event left her with brain damage. The legal battle that developed between her husband and her family demonstrates the difficult legal problems that can trap innocent patients and their families. Her death by starvation and dehydration at the direction of her husband imposed non-voluntary death on an innocent human being and could happen to anyone of us. We cannot count on a general respect for life to protect patients, and we can no longer leave matters to be worked out informally among doctors, patients, and their families. The hard reality is that the presumption has now shifted to favor death, not life.

In fact, there are hidden provisions for rationing that exist in the new Health Care Law and that thus extend the dangers of rationed care to all patients, not only to older people and people with disabilities. More information on the new dangers of rationing in our healthcare is available on the National Right to Life Committee website at www.nrlc.org on pages devoted to the Robert Powell Center for Medical Ethics.

What can we do to protect ourselves and our families from this distressing situation? We now seem to need to have an advanced directive called a "Will to Live" to protect us. A "Will to Live" is a legal document that names someone to make healthcare decisions for us and provides clear, written instructions that will explain that we wish to be given all available healthcare if we are incompetent to direct our own medical care, with specifically stated optional exceptions if, for example, death is inevitably imminent. While the use of this sort of legal instrument cannot guarantee that we would be protected from all medical and governmental challenges to our life, it certainly provides a legal document that should be able to help stand up to such challenges.

There are any number of documented court cases that demonstrate that we will be vulnerable if we do not have such protection. In addition, a Will to Live would provide our families with a tool to assist them in directing our medical care.