

Euthanasia

Two fundamental principles lie at the heart of the Baby Doe debate. They are the “right to life” and the concept of “quality of life.”

When it comes to adults, the “right to life” principle is based on the belief that all persons are fundamentally equal, regardless of their condition, and therefore have a right to the basic entitlements offered by our society. As former U.S. Surgeon General C. Everett Koop said in the context of the Baby Doe cases, “If we do not intrude into the life of a child such as this, whose civil rights may be abrogated? The next person may be you.” The “quality of life” principle allows medical personnel to prolong life if the person will be able to experience a quality of life worth living. This position may support a variety of actions that bring death, including treatment that only alleviates pain, the withdrawal of life-sustaining treatment, or active assistance in dying. (Minow, 1990, p. 314-315)

In the late 1980s and 1990s, these principles were often used in debates surrounding the right of adults to choose when to end their lives, and the right of others to determine when to end another’s life. Two events brought the issues of “right to die” and “right to life” into focus – the case of Nancy Cruzan and the Oregon Death with Dignity Act (1994), and related court decisions.

Nancy Cruzan – The Need for Clear and Convincing Evidence

In 1983, Nancy Cruzan lost control of her car. When she was found, Cruzan was in cardiac and respiratory arrest. Although paramedics revived her, she had been without oxygen for a dozen or so minutes and was believed to have suffered permanent brain damage. She was able to breathe on her own but was being nourished with a gastronomy feeding tube with the consent of her then-husband. Medical experts testified that she was in a “permanent vegetative state” (PVS) and could live another 30 years.

After Cruzan had been declared a ward of the state of Missouri, her parents sought permission to withhold artificial nutrition and hydration so that their daughter would die. A Missouri trial court granted permission to do so, however, the state and Cruzan’s court-appointed guardian *ad litem* appealed that decision to the Missouri Supreme Court. Even though the guardian *ad litem* believed it was in Cruzan’s best interests to have the artificial feeding tube removed, he also felt it was his duty as her attorney to take the case to the state’s Supreme Court because it could be precedent setting.

The Missouri Supreme Court denied Cruzan’s parents the right to withhold nutrition and hydration. Cruzan’s father then appealed to the U.S. Supreme Court asking them to decide if the U.S. Constitution prohibited the state of Missouri from requiring clear and convincing evidence that an incompetent person desires life-sustaining treatment to be withdrawn. In a 5-4 decision, the U.S. Supreme Court held that “a State may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state.” It then said that “clear and convincing evidence” had not been

provided that Ms Cruzan would want her life ended. Previous observations that she had made a year before the accident "... did not deal in terms with withdrawal of medical treatment or of hydration and nutrition."

The story did not end with the U.S. Supreme Court decision, however. Cruzan's father brought evidence from three more of her friends to a Missouri Circuit Court. That court held that the new evidence constituted "clear and convincing" evidence that Cruzan would not want to continue existing in a persistent vegetative state and allowed artificial feeding to be discontinued. Within two hours of the ruling, Cruzan's doctor removed the tube. Cruzan's family maintained a 24-hour vigil with her until she died on December 26, 1990.

New standards

Court decisions related to Nancy Cruzan's life and death set the precedent for many decisions related to ending the life of someone who is unable to state their wishes. In 1914, Judge Cardozo ruled that "adults of sound mind have a right to make decisions about their own bodies." Those decisions include the right to refuse medical treatment or insist that it be withdrawn. The U.S. Supreme Court stated clearly in Nancy Cruzan's case that the state has a constitutional responsibility to protect human life.

[The state has an] interest in the protection and preservation of human life, and there can be no gainsaying this interest. As a general matter, the States -- indeed, all civilized nations -- demonstrate their commitment to life by treating homicide as a serious crime. Moreover, the majority of States in this country have laws imposing criminal penalties on one who assists another to commit suicide. We do not think a State is required to remain neutral in the face of an informed and voluntary decision by a physically able adult to starve to death.

At the same time, the U.S. Supreme Court argued that many of its decisions, beginning with Cardozo, established the right of individuals to make decisions about medical treatment. The issue hinges on balancing an individual's liberty against relevant state interests. Basically, the Court determined that the individual's liberty to make decisions about treatments must be clearly and convincingly stated to ensure that those interests take precedent over the state's interest to protect and preserve human life.

Nancy Cruzan's case focused on what happens when an adult is determined not to be "of sound mind." The U.S. Supreme Court ruling held that it was up to the states to determine what the rules should be. As a result, state statutes began to be developed across the nation.

The first level of rules addresses the rights of adults of "sound mind" to make their wishes known in a "clear and convincing" manner. Living wills, advance directives, powers of attorney for health care and health care proxies allow adults to make their wishes "clear and convincing."

The second level of rules identifies who can make decisions when the evidence is not “clear and convincing” or when the person whose life is considered incapable of making his or her wishes known.

As of October 2009, all but two states – New York and Missouri – had adopted laws or procedures governing health care and end-of-life decisions for individuals who are considered unable to make these decisions due to illness or injury. Forty states and the District of Columbia have laws specifying who has the authority to make decisions for a patient who does not have an advance directive. In many states, a spouse’s wishes are given highest priority, followed by the wishes of adult children, parents and siblings. Some states have different procedures. For instance:

- In Tennessee, the supervising healthcare provider selects the decision-maker after *giving consideration* to the patient's spouse, adult child, etc.
- In Indiana, *any* of those listed (spouse, parent, adult child, sibling, etc.) can decide for the incapacitated patient.
- West Virginia gives the patient's attending physician or an advanced nurse practitioner the right to select the decision-maker from the priority listing, based on who the physician or nurse believes would be the best decision-maker.
- In Connecticut, decision-making is left to the physician in consultation with the next of kin.
- In California, a patient can orally designate someone to make decisions when treatment begins. That designation is in effect only during the course of treatment or illness, or during the stay in the healthcare institution where the designation is made, or for 60 days, whichever period is shorter.
- Under Florida law, a court-appointed guardian has first priority. A spouse is second to a guardian on Florida's priority list. (Marker, 2006)

The New York State Senate passed the Family Health Care Decision Act (FHCDA), but the New York Assembly has yet to do so. This legislation has been in process for 17 years.

In many states, physicians or others can seek judicial approval for decisions on behalf of patients who have no family or others who can decide for them. Only two states, Oregon and North Carolina, allow decisions for these patients to be made without judicial review. In both states, physicians can decide when to provide and when to stop treatment, including life sustaining measures.

Under New York’s pending Family Health Care Decisions Act (FHCDA), when a patient is determined to be incapable of making health care decisions, the hospital must determine if:

- The patient has completed an advance directive or health care proxy.
- A court has appointed an Article 81 guardian.
- The patient has orally appointed a surrogate prior to losing capacity.

If none of these actions have occurred, the patient's close relatives, domestic partner or friends, can select a surrogate who has knowledge of the patient's values and beliefs and will make decisions from a "patient-centered perspective," based on the patient's wishes. If the patient's wishes are not known or cannot reasonably be discovered, the surrogate must act in accordance with the patient's best interests.

The FHODA also requires the hospital's Ethics Committee to become involved if there is a disagreement between a treating physician and a surrogate. Even after a surrogate has been appointed, any wishes that have been clearly expressed by the patient prior to losing decision-making capacity always take priority.

Death with Dignity Acts

"Euthanasia" occurs another person takes an action that results in a person's death. "Assisted suicide" means another person provides the means by which a person can kill him or herself. Two states have laws permitting physicians to provide individuals with lethal doses of medications that the patient can use to end his or her life.

In 1997, Oregon enacted a "death with dignity" law, the first of its kind in the United States. The law became effective five months after the U.S. Supreme Court held that the U.S. Constitution did *not* guarantee the right to assisted suicide. That decision implied, however, that states have the right to decide for themselves whether to permit or prohibit physician-assisted suicide. The state of Washington passed similar legislation in 2008.

The Oregon Death with Dignity Act expands the right of patients to refuse treatment. It is not surprising that when the right to refuse treatment by competent persons was established, a number of legal challenges were filed. A ruling followed that stated if a competent person has the right to refuse treatment, then an "incompetent" person should have access to the same right. Thus, rules were established to allow decisions to be made on behalf of "incompetent" persons if the decisions were determined to be "in their best interests." Because the U.S. Supreme Court has held that states can recognize the right to assisted suicide, that right also can be extended to people who are considered "incompetent." The Washington and Oregon laws require a competence assessment.

The Oregon law states a patient must be:

- 1) 18 years of age or older.
- 2) A resident of Oregon.
- 3) Capable of making and communicating health care decisions for him/herself.
- 4) Diagnosed with a terminal illness that will lead to death within six months.

The attending physician is responsible for determining whether or not these criteria have been met. Unlike a similar law in the Netherlands, the Oregon law *does not* require the patient to be suffering intolerably.

The Oregon Death with Dignity Act (ODDA) is structured around three concepts:

- **Patient self-determination.** The ODDA confers a right to choose the manner and timing of one's death as a logical extension of a terminally ill patient's expansive rights to refuse treatment. The patient with the terminal illness settles the question of the means of death, not the state, medical professionals or religious institutions.
- **Professional immunity and integrity.** The ODDA provides physicians and other health care providers with immunity from prosecution. Advocates supported the freedom of physicians to practice medicine according to their own standards of best practice in caring for the terminally ill. It also involves a shifting view of professional integrity. Supporters of the ODDA argued that the integrity of the medical profession was not *entirely* subsumed by a commitment to healing but should, at the very least, be complemented by physician respect for patient choices.
- **Public accountability.** Advocates of the ODDA sought to provide a regulatory framework and measure of public transparency for the types of hastened-death procedures many were convinced already occurred in secret. (Campbell, 2008)

The ODDA has been the subject of extensive moral, religious, professional and political criticism and debate. The Bush Administration attempted to block ODDA by filing the *Gonzales v. Oregon* lawsuit. Then-Attorney General Alberto Gonzales argued that it was not medically legitimate for physicians to prescribe substances regulated under the federal Controlled Substances Act for the purpose of hastening the death of terminally ill patients. The Supreme Court disagreed.

Since passage of the Oregon Death with Dignity Act, "the question is no longer *whether* physician-assisted suicide should be permitted within medicine, but *how* to regulate and monitor the approved processes effectively. Instead of grappling with the fundamental moral questions, commentary about the act now often sticks to the far more mundane questions of oversight and administration."

One question raised in ODDA legal challenges is the extent to which individuals will feel pressure to end their lives because of a family's unwillingness to bear the emotional and financial cost of care. This is the same issue that played out in decisions about withholding treatment from babies in distress. One analysis of the Oregon Public Health Department data concluded:

...Becoming a "burden" to family and other caregivers emerged as an end-of-life concern for 39 percent of the 341 patients who have used the act in its first decade—a not insignificant number, but still much lower than the percentage of patients who expressed direct self-regarding concerns about loss of autonomy, diminished quality of life, loss of dignity, and loss of control of bodily functions.

Less than 3 percent expressed concerns about the financial implications of treatment. (Campbell, 2008, p. 38)

These numbers were based on patient concerns reported by physicians.

The Terri Schiavo case

In 1990, Terri Schiavo, a healthy, married woman collapsed in her Florida apartment. She stopped breathing and her heart stopped, resulting in extensive brain damage. Schiavo was diagnosed as being in a persistent vegetative state and spent the majority of the next fifteen years in hospitals, nursing homes, rehabilitation centers and hospice care. In 2005, a local Florida court ordered that her life support systems could be disconnected. Schiavo died of the effects of dehydration on March 31, 2005.

Schiavo's husband, Michael, was granted guardianship. In 1998, he applied to the court to have his wife's feeding tubes withdrawn. Her parents objected and the situation made its way to the courts. In summary, the Schiavo case resulted in:

- 14 appeals and numerous motions, petitions, and hearings in the Florida courts;
- Five lawsuits in federal district court;
- Florida legislation that was struck down by the Supreme Court of Florida;
- A subpoena by a Congressional committee to qualify Schiavo for witness protection;
- Federal legislation (the Palm Sunday Compromise);
- Four denials of *certiorari* from the Supreme Court of the United States.

Twenty-six national disability rights organizations presented positions supporting Terri Schiavo's right to continue to receive food and water. According to "Not Dead Yet," "the evidence that Ms. Schiavo would refuse tube feeding is so unclear and conflicted that it does not satisfy legal standards." A number of courts, on the other hand, ruled that Michael Schiavo, as her guardian, had the right to decide that question.

Harriet McBryde Johnson, co-founder of the Disability Rights Committee of the National Lawyers Guild, argued a number of points related to the right of others to decide about Ms. Schiavo's fate, and connections to Death with Dignity legislation, including:

- Ms. Schiavo is not terminally ill.
- Ms. Schiavo is not dependent on life support.
- This is not a case about a patient's right to refuse treatment... The question is who should make the decision for her, and whether substitute decision-maker should be authorized that would result in her death due to starvation and dehydration.
- There is a genuine dispute as to Ms. Schiavo's awareness and consciousness. But if we assume that those who would authorize her death are correct, Ms. Schiavo is completely unaware of her situation and therefore incapable of

suffering physically or emotionally. Her death thus can't be justified for relieving her suffering.

- There is a genuine dispute as to what Ms. Schiavo believed and expressed about life with severe disability before she herself became incapacitated; certainly, she never stated her preferences in an advance directive like a living will.
- Ms. Schiavo, like all people, incapacitated or not, has a federal constitutional right not to be deprived of her life without due process of law.
- In addition to the rights all people enjoy, Ms. Schiavo has a statutory right under the Americans with Disabilities Act not to be treated differently because of her disability. Obviously, Florida law would not allow a husband to kill a nondisabled wife by starvation and dehydration; killing is not ordinarily considered a private family concern or a matter of choice.
- When the issue is the scope of a guardian's authority, it is necessary to allow other people, in this case other family members, to file a legal challenge.
- The whole society has a stake in making sure state courts are not tainted by prejudices, myths, and unfounded fears. While we should not assume that disability prejudice tainted the Florida courts, we cannot reasonably assume that it did not.
- Despite the unseemly Palm Sunday pontificating in Congress, the legislation enabling Ms. Schiavo's parents to sue did not take sides in the so-called culture wars. It did not dictate that Ms. Schiavo be fed. It simply created a procedure whereby the federal courts could decide whether Ms. Schiavo's federally protected rights have been violated.

Although Terri Schiavo died in 2005, the debate surrounding her right to live or die has not gone away. Diane Coleman and Tom Nerney identified some of the continuing trends toward death for people with disabilities in *Guardianship and the Disability Rights Movement*.

While it is clear that most people, in and out of the disability movement, want to have the right to refuse unwanted medical treatment, the alliance of developmental and physical disability groups and their consensus around the Wendland and Schiavo cases demonstrates a growing concern about nonvoluntary and outright involuntary medical killing through withholding of treatment, even food and water. People with disabilities and allies are feeling the pressures toward death from several directions.

First, increasingly throughout the last decade or more (since the fiscal incentives of managed care overtook the health care system), people with disabilities and medical treatment consumers in general experience the need to be knowledgeable advocates to ensure proper health care is provided.

Second, while the Patient Self-Determination Act of 1991 purported to help people effectuate their right to make their own health care decisions, whenever people with disabilities are admitted to a facility, the boilerplate forms they are given are not balanced and objective, but exclusively oriented toward refusal of

treatment. The community is full of anecdotes of people with disabilities pressured by social workers to sign do-not-resuscitate orders.