Schiavo Case Still Triggers Review of Ethics

In the U.S., autonomy tends to trump other medical ethics principles.

BY PATRICIA L. KIRK

DALLAS — Wide public support for continuing Terri Schiavo's artificial nutrition and hydration, despite a diagnosis of persistent vegetative state, indicated growing discomfort among the public about withholding natural life-sustaining substances to bring about death, said Dr. Linda Ganzini, a geriatric psychiatrist, ethicist, and leading scholar in Oregon's Death With Dignity Act.

Dr. Ganzini said that the public reaction to the Schiavo case might have been a reflection of Pope John Paul's 2004 papal allocution on artificial nutrition and hydration (ANH), which stated that "each person has a moral obligation to use ordinary or proportionate means to preserve his/her (own) life."

Dr. Ganzini, who spoke at the annual symposium of the American Medical Directors Association, said, "ANH is ordinary, not extraordinary, even if medically administered." She suggested that the Schiavo case brought the issue to the forefront of ethical debate and raised public awareness of the advantages and weaknesses of advance directives. "Families often don't know a patient's desire," she said, noting that end-of-life decisions frequently are made at bedside and reflect the family's desire rather than that of the patient.

Although Schiavo did not have an advance directive, her husband, Michael Schiavo, presented convincing evidence that his wife would not have chosen to be kept alive in a vegetative state, and the court granted him guardianship, which provided him the legal authority to end his wife's ANH.

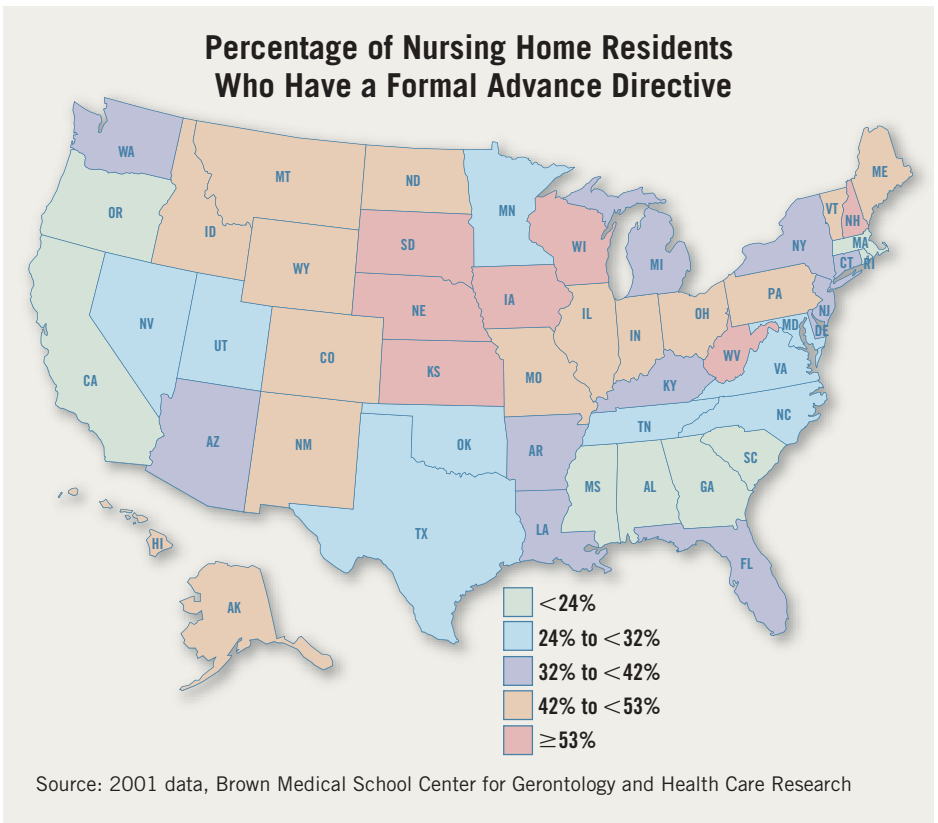
Terri Schiavo's parents, however, appealed the decision and petitioned the court to block withdrawal of their daughter's feeding tube, contending that she was not in a persistent vegetative state (PVS) and that her Catholic faith would have prevented her from choosing to end her own life.

A Florida appellate court upheld the lower court's decision based on the evidence, and the case moved up to the state's Supreme Court, which upheld the opinion of the appellate court. This action set off national debate, spearheaded by the conservative Christian right, on the rights of PVS patients. The conservative Christian right used its political muscle to convince the Florida legislature to enact a law giving the governor authority to override judicial rulings involving patients with PVS.

The Florida Supreme Court ultimately deemed the Florida legislature's action unconstitutional. However, Dr. Ganzini said, the controversy signaled growing support for fundamentalist values and triggered examination of medical ethics issues.

"The Schiavos would have opposed stopping ANH even if there had been an advance directive," Dr. Ganzini said. "They clearly still saw her as a [living] person."

The Schiavo scenario, however, caused the medical community to revisit the basic tenets of medical ethics in relationship to end-of-life treatment decisions and to question long-held beliefs, she said.



Source: 2001 data, Brown Medical School Center for Gerontology and Health Care Research

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Four basic principles underlie medical ethics:

- **Autonomy.** There is a moral right to choose and follow one's own plan of life and action and control one's own body, protecting it from unwanted intrusions, including the right to refuse treatments, food, or fluids.
- **Beneficence.** A clinician's actions must benefit the patient by improving quality of life or chances of survival or by preventing harm.
- **Nonmaleficence.** Clinicians must do no harm; they must not kill or cause pain, suffering, or incapacity of patients.
- **Justice.** Treatment must be equitable and fair.

In the United States, autonomy tends to trump other ethics principles, Dr. Ganzini said. She noted, however, that a patient's legal right to autonomy is measured by the patient's decision-making capacity, or ability to understand and appreciate the nature and consequences of health care treatment decisions, including risks, benefits, and alternatives.

In other words, if decision-making capacity is deemed absent, then a surrogate, who might be a health care agent with durable power of attorney, a legal guardian, or the patient's next of kin, is appointed to make end-of-life decisions based on an advance directive. They also may substitute judgments based on conversations with the patient or knowledge of the patient's values. In the absence of either of those, the best interest of the patient is considered—relief of suffering, preservation of function, and quality and quantity of life.

The legal framework regarding autonomy mandates that competent patients have the right to refuse medical treatments, even if refusal may hasten death, and that incompetent patients have the same right but that surrogates exercise it for them. Surrogates, however, have a set of standards they must apply, one of which recognizes that there is no difference between withholding and withdrawing treatment.

Dr. Ganzini noted that the "rule of double effect" often comes into play when a medical professional acts as a surrogate. This rule refers to giving a treatment to ease suffering with the knowledge that the treatment may hasten end of life, such as giving morphine to ease pain, knowing it might cause death. She noted that Thomas Aquinas addressed this issue by suggesting that easing pain and suffering overrides other ethical concerns, as long as no maleficence is intended.

Dr. Ganzini said that examining beliefs is a healthy process for the medical community. "It challenges us to question things we have come to accept as truth, such as the notion that 'pneumonia is the old man's friend.' " She noted that a 2002 study of 662 dementia patients with pneumonia reported higher discomfort in patients who did not receive antibiotics before death, with discomfort escalating shortly before aspiration.

Consequently, medical professionals are mapping goals of care for patients with terminal diseases, based on research and ethical practices.

For example, new treatment protocols for patients with amyotrophic lateral sclerosis take into consideration that these patients usually have decision-making capacity, and study findings suggest that, although inserting a feeding tube doesn't necessarily prolong life, it is recommended at onset of swallowing difficulties before lung capacity declines. A feeding tube improves nutrition, lessens fatigue and fear of choking, and alleviates the struggle to eat.

Similarly, studies indicate no survival benefits associated with artificial nutrition and hydration for cancer patients, but in terminal cancer patients, ANH may improve the chance of maintaining cognition. About 90% of terminal cancer patients develop episodes of delirium in the final weeks of life. ANH has been shown to decrease the potential for onset of delirium and opioid toxicity—agitated delirium—which also are markers of a bad death.

Research also suggests that parenteral hydration in terminal cancer patients may reduce hallucinations, fatigue, myoclonus, and the need for sedation in terminally ill cancer patients. In addition, numerous studies indicate that ANH provides no survival benefits in patients who have severe dementia and are in long-term care facilities.

Although there are no randomized trials on tube feeding (TF) in dementia patients, experience suggests that it probably does not prevent aspiration or improve pressure sores because TF promotes restraint use, immobility, fecal incontinence, and the use of psychotropic medications.

However, a study of "beliefs" of 195 family physicians and internists on benefits of TF found that the majority believed it decreased aspiration pneumonia (76%); improved decubital ulcers (75%), survival (61%), and functional status (27%); and is a standard of care (50%).

Studies have also found that one-third of long-term care patients would chose TF if they could no longer eat, most citing prolonged survival; 47% of physicians believe nursing home staff request TF; and 67% of physicians believe a nutritionist or speech pathologist requests it.

Caregivers agree to the use of TF to increase patient comfort (22%), extend life (18%), or increase strength (14%). Terminal patients are increasingly choosing to hasten the end of life by either voluntary refusal of food and fluids or physician-assisted suicide.

An Oregon study found that the most common reasons for patients wanting to hasten the end of life were fatigue or pain and fear of worsening fatigue or pain. The study noted that impressions of hospice staff indicate that these patients want to control their circumstances of death and fear the loss of their independence and becoming a burden on others.

"It's interesting that Terri Schiavo got so much attention," said Dr. Ganzini. "Catholic theology and the pope's opinion that choice should be life sustaining evolved over centuries." The response to the Schiavo case serves as a reminder "that people have different ways of thinking about this.

"Clearly people are using different formulations to come to decisions about life and death issues," she added, stressing that physicians must step up to the plate and take part in the decision-making process; otherwise, "families are left feeling guilty about pulling the plug on a loved one."