

FLORIDA BIOETHICS LEADERS' ANALYSIS ON HB701
MARCH 7, 2005

Preamble

The undersigned are academicians who have long studied end-of-life care, advise and educate many Florida hospitals and other health care institutions on this and related issues and are responsible for the education of most medical students in Florida. Most of us are leaders of the Florida Bioethics Network, a statewide membership organization created in 1991 to provide education and resolve practical problems and controversies in health care ethics. Because the Florida Bioethics Network as such does not take positions on proposed legislation, the analysis here is that of the individual authors. Several of us were involved in the Panel for the Study of End-of-Life Care, a legislatively mandated group which, in 1999, guided the Legislature in the last major revision of FS765, which HB701 seeks to amend. That revision assigns the Florida Bioethics Network the role of certifying "community-based" ethics committees that address end-of-life decisions by guardians for patients in persistent vegetative states in institutions without their own standing ethics committees (FS765.404(2)). Additionally, as individuals and ethics network officers, several of us have collaborated in various ways with and provided expert services to Florida's Departments of Children and Families, Corrections, Elder Affairs and Health.

This invited analysis addresses *ethical* aspects of the proposed legislation. A legal analysis of the measure by one of the authors is available at http://www.miami.edu/ethics/schiavo/hb701_cerminara.pdf.

Commentary

House Bill 701 is a well-intentioned response to the tragic case of Theresa Marie Schiavo. We are, however, of unanimous and emphatic belief that the proposed measure

- Would impose impossible burdens on physicians and patient surrogates, proxies and guardians.
- Would establish insurmountable barriers to Floridians' exercise of uncontroversial rights to refuse burdensome medical treatment.
- Misjudges the medical nature of artificial nutrition and hydration and the ethical issues involved in withholding and withdrawing such interventions.
- Misunderstands the nature and importance of disability in end-of-life care.

Imposition of Impossible Burdens on Physicians and Patient Surrogates, Proxies and Guardians

Physicians have an uncontroversial moral obligation to comply with the preferences of their patients with regard to the withholding, withdrawing or administration of life-sustaining treatment, including medically supplied artificial nutrition and hydration. To require a physician to participate in the administration of medically supplied nutrition and hydration when the physician knows that patient did not desire such treatment is to ask

that physician to act contrary to his or her moral obligations. A physician has no control over whether a patient executes a written advance directive, so the physician's best hope of knowing his or her patient's wishes regarding end-of-life care is to discuss the matter with the patient, in advance, in much the same manner as other possible future treatments.

Under HB701, the physician's discussions will be to little or no effect unless those discussions are eventually memorialized in a written advance directive. Most persons are uncomfortable discussing end-of-life care with others, including their physicians. Even assuming a patient were comfortable, such comfort level may not extend to precision in terminology and details. In practice, many end-of-life care discussions focus on patients' values and treatment goals rather than on predictions of precise medical conditions and treatment. Indeed, they must do so, for it is impossible to predict with precision details of future conditions and treatments. For that reason, we and others who educate physicians and future physicians advise them to proceed in just this fashion. HB701's restrictive definition of the term "express and informed consent" would negate such discussions, effectively requiring patients to execute written advance directives to authorize withholding or withdrawal of medically supplied nutrition and hydration. Furthermore, under HB701's definition of that term, such withholding or withdrawal would be possible only if a patient and his or her physician had foreseen and discussed the patient's precise future condition and treatment, as well as the state of future medical technology — matters which are, often, impossible to foresee.

Moreover, HB701 would have the effect of undermining, if not reversing, a quarter-century of bipartisan and nonsectarian agreement that medically supplied nutrition and hydration should be regarded as a medical intervention and in this way the same as any other medical treatment. This consensus is, indeed, already incorporated in Florida law (FS765.101(10)). HB701 would undermine progress demonstrated by the hospice movement, substantially reduces the powers of court-appointed guardians, and eliminate the best-interest standard for surrogate, proxy or guardian decision making regarding medically supplied hydration and nutrition. These changes would undermine and destabilize the well-founded health care expectations of all Floridians.

Barriers to Exercise of Uncontroversial Rights to Refuse Burdensome Medical Treatment

HB701 requires too much evidence of a patient's wishes — so much evidence that most people who would want to have medically supplied nutrition and hydration withheld or withdrawn would end up receiving it against their wishes.

The bill appears to be based on an unrealistic expectation that many patients will execute written advance directives. (See proposed section 765.604(2).) Written advance directives undoubtedly are valuable and can constitute the best evidence of a patient's wishes once that patient becomes incapable of making medical decisions. However, the vast majority of people, although saying they want advance directives, do not execute them. Those persons would be deprived of their bodily integrity under HB701. The bill effectively requires either execution of a written advance directive or the previously

discussed impossible level of conversational specificity to prevent a patient's being subjected to unwanted medical treatment.

Moreover, the proposed measure appears to misunderstand that percutaneous endoscopic gastrostomy (PEG) tube placements are surgical interventions. To use the term "feeding tube" in this context is a misnomer; "feeding" requires some level of human interaction with and appreciation of food. Use of a PEG tube implanted through the skin and stomach wall for infusion of liquid nutrient compounds over long periods of time does not constitute "feeding" in any ordinary sense of the word. To require that patients explicitly refuse such an intervention would force most who would reject it to be subjected to the abridgment of the most fundamental kind of moral, natural and civil right – the right to be free of bodily invasion without consent.

Importance and Effect of Medically Supplied Artificial Nutrition and Hydration

Until the Schiavo case, medically supplied hydration and nutrition were widely and uncontroversially agreed to be life-prolonging interventions – no different than mechanical ventilation, dialysis or the application of an electrical charge to restore normal heart rhythm. All are generally regarded as temporary measures to assist a person whose body cannot perform these functions on its own. Appropriate placement of a PEG tube is based on evidence that the intervention will assist the body until it recovers to a point at which it can function without such assistance. That is, PEG tubes, ventilators and the like are medically appropriate only when used as a "bridge to recovery," not as a way to prolong the dying process in the patient population that would be affected by HB701.

Perhaps most important, the proposed legislation has at its core the mistaken presumption that the withdrawal or withholding of medically supplied hydration or nutrition is somehow unpleasant, onerous or even painful. This is simply false, and has been refuted in the expert literature. It is important to make a distinction between hunger and thirst, which (like suffering) are psychological states, and malnutrition and dehydration, which (like pain) are physical, or physiological, states. Although many people think of a death following withholding or withdrawal of nutrition and hydration as being uncomfortable or painful, research indicates that this is not the case; lack of nutrition and hydration, in fact, may serve as an analgesic for dying patients. In any case, this could only be a concern for a patient who is conscious and thus able to suffer. Many incapacitated patients cannot experience hunger, thirst or their satiation. And it is physiologically impossible for a patient in a persistent vegetative state to experience anything at all, whether on a PEG tube or not.

It is therefore essential to put in bold face the fact that terms like "starvation," as used in the title of HB701, are inaccurate, confusing and emotion-laden. Everyone rightly agrees that "starving someone to death" is abhorrent. But to suggest that the withdrawal or withholding of medically supplied artificial hydration and nutrition constitutes such a thing is medically false, morally mistaken and socially misleading. It would be a tragedy for the people of Florida if our Legislature were to make this error.

Nature and Importance of Disability in End-of-Life Care

Through its title, the “Starvation and Dehydration of Persons with Disabilities Prevention Act,” HB701’s addition to FS765 refers to the rights of the disabled. Thus the proposed legislation confuses the distinction between individuals whose objective circumstances and prognosis are vastly different. Because they are not relevantly similar except for one feature – decisional incompetence – it is ethically illicit to insist that they be treated alike; to do so is a failure of respect for persons. While this error may stem from a misunderstanding occasioned by the Schiavo case, we should not fail to consider the far broader and erosive effects of HB701 on a much larger patient population. While a few partisans deny or reject the medical diagnosis of persistent vegetative state in the Schiavo case, we and experts we have consulted are unaware of any *credible* medical dissent from the PVS diagnosis. Such a diagnosis is tragic and devastating. It means the person who is diagnosed thus cannot and will not ever hear a voice, feel a touch or see anything, ever. This is the unhappy fact of the case, according to the best medical evidence. Those who deny it appear to do so without medical expertise or an understanding of its implications. Those who cite videos of Ms. Schiavo, for instance, as evidence that she is actually sentient and cognitively intact (or even “minimally conscious”) are unaware or in denial of the brute fact that such images are perfectly consistent with a PVS diagnosis – and therefore do not constitute evidence of awareness, cognition or sensation.

Despite extensive advocacy on this point, it is widely and accurately agreed that a person who is permanently unconscious is most certainly not disabled in either the ordinary or the medical use of the term. To be disabled is to be in some way physiologically harmed or different such that the patient is unable in varying degrees to do or experience things that other people do or experience. If someone is unable to do or experience *anything*, it is incoherent to suggest that such a person is *disabled* in the sense of having less or different-than-customary capacity. To be permanently unconscious is not to have limitations, impediments or decreased functions. These properties, however, are precisely and exclusively required to define disability; without these characteristics, one is not disabled. We are deeply saddened that some members of the bona fide disability community – a community underserved in Florida and elsewhere – have acquired the false belief that Ms. Schiavo is “disabled” or “differentially abled.” She is not.

Case Example

The main problem with the proposed change to FS765 may best be illustrated by considering its application to a concrete case. A 65-year-old male has been diagnosed with terminal bone cancer, a condition for which the pain is notoriously difficult to control. He writes an advance directive that says, “when my pain becomes so unbearable that the only way to control it is to give me large doses of narcotics, I want all forms of life sustaining treatment discontinued, so that my dying process is not prolonged.” Florida law permits all of these choices. If HB701 becomes law, his wife, whether she is named as his surrogate or is the first in line to serve as his proxy, may direct:

- 1) that no cardiopulmonary resuscitation be given if he has a cardiac arrest;
- 2) that mechanical ventilation be withheld or withdrawn;

- 3) that if his kidneys fail, no dialysis be initiated;
- 4) that if he contracts pneumonia, no aggressive antibiotic therapy be initiated;
- 5) that if surgery seems to be indicated for other conditions, none take place;
- 6) that if he has a hemorrhage, and is bleeding internally, no blood transfusions be given.

She may make all the above decisions and more without his specifically naming any of these procedures, but since he did not specifically say, “no percutaneous endoscopic gastrostomy tubes,” she could not refuse surgical implantation of a tube for the medical administration of nutrition and hydration. Even though his rationale for refusal would be the same, and there is no reason to think that his refusal would apply any less to medical nutrition and hydration than all the other life-sustaining treatments, HB701 would force a physician to surgically implant a tube into the patient’s stomach in order to pump a nutrient solution that would have the effect of prolonging his dying.

There is no good reason to single out medically supplied artificial hydration and nutrition as an intervention requiring explicit refusal in advance. Why not ventilator support? Dialysis? We fear that if Ms. Schiavo were being maintained on a ventilator, we would be commenting on the “Suffocation of Persons with Disabilities Prevention Act.” This emotionally charged case ought not be allowed to subvert longstanding, bipartisan agreement on rights to refuse treatment and on the duties of surrogates, proxies and guardians to refuse such treatment when appropriate.

Conclusion

We are honored by the invitation to analyze important proposed legislation. As well as educators and scholars, we write as concerned Floridians who fear that this legislation emerges in an ideologically charged environment, and is not grounded in sound science or consistent ethics.

We have been proud to serve the Legislature in its previous efforts to improve Florida’s laws regarding end-of-life care, and hope to help ensure that these laws are based on the highest scientific and ethical standards.

The signers of this statement are listed in alphabetical order. Their affiliations are for identification only. The views expressed here do not, of course, represent any official position of their institutions.

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