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### **Ethical Issues: Reflections on HB 905**

In times of crisis there are opportunities to grow and learn. With the suffering and demise of Terri Shiavo patients, families, and health care providers again find themselves in doubt as to what to do in the midst of very personal and difficult end of life decisions that may be forced to yield to the exigency of social and political ends. Not unlike Quinlan in the 1970s and Cruzan in the 1980s, the personal freedom and privacy arguments of Shiavo have overcome the socio-political morality of the day, but not without a price. Physicians' judgments may be influenced as they continue to struggle with the notion of futility and contemplate how other people and society might judge them if treatment decisions made in the interest of the patient are not necessarily in lock step with contemporary moral precepts. With Shiavo many physicians again feel vulnerable to the possibility of difficult cases becoming public spectacles, locked in legal and political battles that objectify patients and the profession in pursuit of socio-political ends. As Timothy Quill puts it, "Distortion by interest groups, media hyperbole, and manipulative use of videotape have characterized this case and demonstrate what can happen when a patient becomes more a precedent-setting symbol than a unique human being."<sup>ii</sup>

In Shiavo, as well as Cruzan, the courts have affirmed the right of surrogate decision makers to decide for the patient when the patient is incapacitated. But, the courts have also consistently affirmed states' rights to devise their own standards of evidence about patients' wishes and standards of treatment when those wishes are not known.<sup>ii</sup> In the Missouri legislature HB 905 is now being considered, having been introduced by 30 co-sponsors. Several advocacy groups have given testimony in favor of the bill, many of whom argue that feeding tubes should never be withdrawn unless the patient cannot tolerate tube feedings or it is otherwise medically contraindicated. HB 905 would do the following if made law:

- Criminalize (Class D felony) withholding or withdrawing of artificial nutrition or hydration from persons incapacitated and incapable of speaking for themselves unless a written directive is in place prohibiting such intervention.
- Not allow a guardian or legal surrogate to authorize withholding or withdrawing of artificial hydration and nutrition unless the patient has a written directive specifically instructing them to do so.
- Remove authority of the probate court to authorize removal or withholding of tube feedings absent a written directive.

HB 905 gives the written directive absolute authority as the ruling document in end of life decisions regarding feeding tubes. In essence, without a written directive it doesn't matter if clearly articulated verbal statements have consistently been made by the patient

to the family or their health care providers. This law would set a much higher standard than Cruzan that recognized both written and verbal evidence as to patients' wishes. With no written document incapacitated persons would be relegated to forced interventions even if family, physicians, nurses, and other team members agree that there is no hope of recovery, and when there is clear (albeit unwritten) evidence that the patient would not want to be kept alive in that way. Such a law will have a huge impact on the way we provide end of life care and the context within which it is provided.

Presently about 20% of patients admitted to hospital have health care directives. Most have chronic conditions such as chronic heart and lung disease, cancer, or dementia, placing them at high risk for death. Efforts to modify this behavior and improve completion rates of written directives have, for the most part, failed. A less sinister outcome of Shiavo may be that members of society, specifically physicians and their patients, may learn of the importance of completing a written health care directive and making their preferences about end of life treatment well known to loved ones and their physicians well in advance of advancing disease.

I agree with Art Caplan that out of this tragedy much can be learned: we, as physicians, must begin and continue the dialogue with our patients and encourage them to write their wishes down; we must encourage lawmakers not to overreact and remind them that difficult decisions regarding patient treatment should be made privately and at the bedside--not in the courts, on the floor of the legislature, or in executive chambers; we must encourage organized medicine, nursing, and hospice care in America to reflect on their values and participate in the national dialogue about Shiavo and other difficult health care issues; most importantly, we collectively must respect personal choice and foster the fundamental right of personal autonomy that allows competent patients to accept or refuse treatment, while also recognizing society's obligation to protect its most vulnerable members.<sup>iii</sup>

Terri is gone, but her memory and ethical legacy remain. History has been made and we as a society will never be the same. We, as a profession can respond by learning more about the issues and helping our patients to make informed and well documented decisions, and by assisting our political leaders to do the same—it's our choice.

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<sup>i</sup> Quill T. Teri Shiavo—A Tragedy Compounded. *NEJM*. 2005; 352 (16) ; 1630-1633

<sup>ii</sup> Gostin L. Life and Death Choices after Cruzan. *Law Med Health Care*. 1991; 19:9-12

<sup>iii</sup> Caplan A. What can we Learn from the Shiavo Case? MSNBC.com march 31, 2005