TESTIMONY OF SUSAN KLEIN
IN OPPOSITION TO HB 1146
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On HB 1146, the "Adult Health Care Consent Act"
February 5, 2014

HB 1146, the "Adult Health Care Consent Act," has important positive features, among which are its provisions allowing resort to judicial relief to contest a health care decision and preventing "medical action for a pregnant patient that will put the [unborn child] at risk of death or serious physical injury, except to protect the life of the mother"– although, as I will point out later in my testimony, both of these provisions need strengthening.

Unfortunately, the bill also has a number of deficits that place vulnerable patients, especially people with disabilities and older people, at risk. These deficits would require substantial amendments to the bill to ensure that Missouri law adequately defends those most in need of protection from nonvoluntary denial of life-preserving medical treatment, food, and fluids.

1. Food and Fluids

First, the definition of "health care" in the bill is sufficiently ambiguous that it could be interpreted to include provision of medically administered food and fluids. Missouri law now provides special protections against deprival of nutrition and hydration, and it is important that HB 1146 not undermine these.

Under Missouri's current law governing a "declaration," popularly known as a "living will," the procedures which may be rejected do not include "the performance of any procedure to provide nutrition or hydration."1 Under the Durable Power of Attorney for Health Care Act, "If a patient wishes to confer on an attorney in fact the authority to direct a health care provider to withhold or withdraw artificially supplied nutrition and hydration, the patient shall specifically grant such authority in the power of attorney. This limitation shall not be construed to require that artificially supplied nutrition and hydration be continued when, in the medical judgment of the attending physician, the patient cannot tolerate it."2

That statute goes on to say, "[N]o attorney in fact may, with the intent of causing the death of the patient, authorize the withdrawal of nutrition or hydration which the patient may ingest through natural means."3 It requires that, "Before an attorney in fact or physician may authorize the withdrawal of nutrition or hydration which the patient may ingest through artificial means, the physician must: (1) Attempt to explain to the patient the intention to withdraw nutrition and hydration and the consequences for the patient and to provide the opportunity for the patient to refuse the withdrawal of nutrition and hydration; or (2) Insert in the patient's file a certification that the patient is comatose or consistently in a condition which makes it impossible for the patient to understand the intention to withdraw nutrition and hydration and the consequences to the patient."4

The Missouri Supreme Court decision in *Cruzan v. Harmon*5 remains precedent in this state. Noting that, "common sense tells us that food and water do not treat an illness, they maintain a life",6 the state Supreme Court held, " no person can assume that choice ["to cause the death of an incompetent" by stopping feeding by tube] for an incompetent in the absence of the formalities required under Missouri's Living Will statutes or the clear and convincing, inherently reliable evidence [of the patient's informed refusal] absent here".7

In short, under current Missouri law, a surrogate may not prevent an incompetent patient from receiving assisted feeding and fluids, so long as the patient can tolerate them, in the absence of specific authorization in a health care power of attorney document or of clear and convincing, inherently reliable evidence the patient rejected it.

To preserve the protections of current Missouri law against nonvoluntary starvation and dehydration, either the definition of "health care" in HB 1146 needs to be amended explicitly to exclude from its scope the provision of nutrition or hydration or else the authority of surrogates to direct their withholding or withdrawal needs to be carefully limited so as not to exceed what is authorized in existing Missouri law.

2. Checks are Needed on the Ability of Physicians to Disqualify Surrogates Deciding For Life-Preserving Treatment

Second, one seemingly praiseworthy provision in HB 1146 is troubling because it establishes a means by which physicians who strongly believe that a patient should die because of a supposed poor quality of life can disregard a surrogate's directions to provide life-preserving treatment.

Section 191.1302.3 of the bill provides, "If an attending physician or other health care professional has reasonable cause to make a report of abuse or neglect of the patient under [specified sections of Missouri law], the individual to be reported as the alleged perpetrator shall not be given priority or authority . . . regardless of the purpose of the treatment."

The intent of this provision is laudable. Certainly there is reason to question the validity of someone who has abused or neglected the patient making medical decisions for that patient. However, note that the reported individual is completely excluded from being a surrogate simply because of the doctor's view that there is reasonable cause to make a report, not because of any judicial or even administrative finding that the report is warranted.

Why is this potentially dangerous? Sadly, there is an increasingly pervasive view among many in the medical profession – not all – that preserving the life of someone whose quality of life they deem to be too poor is itself a form of abuse. The title of one law review article typifies this position: "When Vitalism is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment".8 A physician who agreed with the perspective of that article's author could unilaterally disqualify a pro-life surrogate because the doctor considered a decision for life-preserving treatment to constitute abuse of the patient – very erroneously, we would argue, but sincerely under his or her quality of life ethic.

Other provisions in the bill authorize a doctor to override a pro-treatment decision by a surrogate. Section 191.1308.2 states that the provisions of the act "do not authorize the provision of health care to a patient who is unable to consent if the attending physician or other health care professional responsible for the care of the patient has actual knowledge that the health care is contrary to the patient's unambiguous and uncontradicted instructions expressed at a time when the patient was able to consent." This subsection means that if, say, the patient's spouse directed life-preserving treatment, and the patient's doctor suddenly asserted that years earlier the patient had told the doctor she wouldn't want such treatment, the doctor's unilateral assertion at least initially would prevail. Section 191.1308.1 similarly would allow a doctor to disregard a surrogate's direction for treatment based on the doctors' judgment that life-preserving treatment "is contrary to the religious beliefs of the patient." Section 191.1302.5 would allow a doctor to do so based on the doctor's claim that the patient "did not want [the surrogate who is directing treatment] involved in decisions concerning the patient's care." In these circumstances, however, at least the disqualified or disregarded pro-life surrogate could petition the probate court under section 191.1302.2 in a manner that effectively challenged her exclusion or the doctor's decision to deny treatment. Moreover, Section 191.1308.3 affirms that the rest of the

bill's provisions "do not limit the evidence on which a court may base a determination of a patient's intent in a judicial proceeding," so the doctor's assertions could be subject to rebuttal and a neutral assessment of their accuracy.

In contrast, the ability of a doctor to disqualify a surrogate by alleging abuse is seemingly absolute. Apparently, even if the allegation is formally determined to be unsubstantiated, neither the probate court nor any other authority could reinstate the wrongfully accused surrogate. By this means, a doctor ardently committed to the quality of life ethic could disqualify any higher priority pro-treatment surrogate, replacing that person with a lower-priority anti-treatment surrogate.

3. Inconsistency Between Definition of "Unable to Consent" and "Incapacitated"

Third, the bill introduces a definition of "unable to consent" which is to trigger the authority of surrogates, including "An attorney-in-fact appointed by the patient in a durable power of attorney for health care," yet the Durable Power of Attorney for Health Care Act makes an attorney-in-fact's authority go into effect when the patient is "incapacitated" as defined in section 404.805.1(2)9 of that act. There are significant differences in the definitions of the two terms. The bill as written would thus introduce an inconsistency into Missouri law concerning when an attorney-in-fact is authorized to make health care decisions for the patient.

4. Need to Ensure Life-Preserving Treatment Pending Outcome of Court Proceedings

At the outset of my testimony, I praised two aspects of HB 1146: that it has provisions allowing resort to judicial relief to contest a health care decision by a surrogate and preventing "medical action for a pregnant patient that will put the [unborn child] at risk of death or serious physical injury, except to protect the life of the mother." Unfortunately, even these require important amendments.
Fourth, then, with regard to judicial review of disputes concerning the withdrawal or withholding of life-preserving medical treatment, it is important explicitly to provide in the legislation that during the litigation the court is to issue appropriate orders to preserve the life of the patient. Obviously, the case would be mooted and the as-yet-unadjudicated right of the patient to life would be irreversibly lost if she or he was forced to die before the court's final judgment.

5. Need to Provide for Life-Preserving Treatment for a Pregnant Patient

Fifth, the provision preventing "medical action" risking the death of an unborn child in the case of a pregnant patient also requires amendment to clarify that the prohibited "medical action" includes not just affirmative acts that might cause the child's death, such as an abortion, but also the withholding or withdrawal of life-preserving treatment from the child's mother that would necessarily result in the death of the child within her womb. As we have seen from the recent widely-publicized case in Texas, explicit statutory protection for the unborn child is also needed when the mother has been declared brain dead.

Conclusion

In conclusion, Missouri Right to Life recognizes that family members may need to make appropriate health care decisions for patients currently incapable of making them themselves who have not designated someone through a durable power of attorney for health care. However, any legislation addressing this sensitive area, rife with dangers for the most vulnerable patients, needs to be carefully crafted to protect the presumption that patients will receive food and fluids and to ensure that pro-treatment decisions by surrogates will be respected and implemented. In cases of doubt or dispute, it is better to err on the side of preserving life.

Without significant amendment, HB 1146 does not meet that standard. While Missouri Right to Life is glad to work with interested parties in the development of an appropriate bill in this context, we must ask the committee not to advance HB1146 in its present form.

[1] Section 459.010(3) R.S.Mo.

[2] Section 404.820.1 R.S.Mo.

[3] Section 404.820.2 R.S.Mo.

[4] Section 404.820.4 R.S.Mo.

[5] 760 S.W.2d 408 (Mo. 1988) *affirmed sub nom.* Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261(1990).

[6] *Id.*, 760 S.W.2d at 423.

[7] *Id.* at 425.

[8] 79 Ind. L.J. 1 (2004).

[9] "Incapacitated" is defined as " a person who is unable by reason of any physical or mental condition to receive and evaluate information or to communicate decisions to such an extent that he lacks capacity to meet essential requirements for food, clothing, shelter, safety or other care such that serious physical injury, illness or disease is likely to occur".