

Written Testimony for a Hearing on H.B. 3520 before the Human Services Committee of the Texas House of Representatives

April 12, 2011

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Dear Chairman Raymond and Members of the Human Services Committee:

Thank you for allowing me this opportunity to present testimony regarding House Bill 3520. In order to make this written testimony as useful as possible to the Committee and its staff, I have organized my testimony into the following six sections:

1. My Professional Background
2. My Interest in H.B. 3520
3. Section 166.046 is Unique.
4. By Adding a “Treat until Transfer” Requirement to Section 166.046, H.B. 3520 Negates Its Effectiveness.
5. There Are Alternatives to Section 166.046.
6. Section 166.046 Violates Procedural Due Process.

1. My Professional Background

I am a law professor. Since 2005, I have been focusing most of my research on the legal issues concerning end-of-life treatment disputes. I have written numerous law review articles, medical journal articles, and bioethics journal articles on this topic.¹ I have drafted institutional futility policies. I have participated in the litigation of these issues in courts from New Jersey to Alaska. And I have testified before the President’s Council on Bioethics. I am currently a legal consultant to the American Thoracic Society and other professional medical associations engaged in updating international policies on this issue.

¹ A list of my publications is available at www.thaddeuspope.com. I also track relevant developments at the Medical Futility Blog (www.medicalfutility.blogspot.com).

2. My Interest in H.B. 3520

As a scholar of end-of-life treatment disputes, I have closely followed the development of Texas Health and Safety Code Section 166.046. My research includes the review of the following materials that specifically discuss this law:

- Scholarly articles (in bar journals, law reviews, medical journals, bioethics journals)
- House and Senate bills and hearings in 2006, 2007, and 2009
- Cases before state and federal courts in Texas
- Numerous discussions with Texas hospital ethics committee chairs and other involved medical professionals
- Discussion and debate with core authors of the Texas Advance Directives Act
- Newspaper articles, websites, blog posts

Of course, my study of end-of-life dispute resolution mechanisms is not limited to Texas. I have been examining and analyzing how other jurisdictions in the United States, Canada, and abroad approach the same problems that Section 166.046 was designed to handle. Nevertheless, because the law in Texas is unique, it has been of special interest.

3. Texas Health & Safety Code Section 166.046 is Unique in the United States.

Many other states have so-called unilateral refusal provisions. These statutes permit healthcare providers to decline life-sustaining medical treatment that they deem medically inappropriate, even if the patient's surrogate disagrees. These statutes also confer criminal, civil, and disciplinary immunity on a provider who chooses to decline treatment pursuant to specified standards.²

However, in contrast to Texas, these other state statutes link the statutory safe harbor to the medical standard of care. The provider may refuse desired life-sustaining treatment only if the requested treatment is "medically inappropriate" or "contrary to generally accepted healthcare standards." But whether any particular treatment for any specific patient actually meets these standards is very uncertain. There is enormous variability in end-of-life medicine. Providers can almost never be sure whether or not they are within the scope of the statutory safe harbor protection. These providers must make unilateral refusal decisions in the "shadow" of the court system. Due to the legal risk averseness of healthcare providers, they generally do not use these statutes.

Texas providers are not similarly "chilled" from declining treatment that they deem medically inappropriate. Texas providers can make treatment decisions **outside** the shadow of the court system. Section 166.046 makes the physician's own institutional

² Medical futility disputes typically concern the appropriateness only of life-sustaining medical treatment, of technological interventions. Objecting providers will continue to provide palliative care. Therefore, the conflict is not so much between "treatment" and "no treatment," as between the **type** of treatment.

ethics committee the forum of last resort in medical futility disputes. Once the committee agrees (as it usually does) with the referring physician that the desired life-sustaining treatment is inappropriate, that decision is final and unreviewable.

A second key difference between Texas and many other states concerns what happens in Texas, if the ethics committee agrees with the attending physician that the surrogate-requested treatment is inappropriate. In that situation, the committee serves the surrogate with its written decision. The surrogate then has ten days to find a transfer facility willing to provide the treatment that the current facility is unwilling to provide. If no transfer is found (and usually none is), then the treating facility may stop life-sustaining treatment over the objections of the surrogate. In contrast, many other states balance the provider's rights and the patient's rights by permitting a provider to stop treatment only after finding a new, replacement provider. In other words, these states require objecting providers to "treat until transfer."

4. By Adding a "Treat until Transfer" Requirement to Section 166.046, H.B. 3520 Negates Its Effectiveness.

After an ethics committee serves its written decision on the surrogate, Section 166.046 requires that the provider make a "reasonable effort" to transfer the patient. But this obligation is limited to ten days. After all, these transfers are rarely found. The required state-developed "list" of potential transfer facilities has been of little use in effecting transfers.

There are several reasons that transfers may not be found. First, other facilities may agree with the treating facility that the requested treatment is non-beneficial and inappropriate. Second, the patient may be uninsured or underinsured. So, other facilities refuse to avoid the financial burden of expensive uncompensated treatment. Third, other facilities may simply want to avoid a conflict-ridden situation.

Recognizing this fact, other states also limit the provider's duty to attempt transfer. California requires that providers continue care only "until a transfer can be accomplished or until it appears that a transfer cannot be accomplished."³ Virginia requires fourteen days.⁴

In contrast H.B. 3520 proposed to change the ten day limit in 166.046 into a "treat until transfer" requirement.⁵ Because a transfer will typically not be found, this treatment until transfer mandate means that, to earn the safe harbor immunity, Texas providers would have to continue providing the disputed treatment indefinitely, no matter how non-beneficial or cruel to the patient. In short, a "treat until transfer" requirement practically

³ Cal. Prob. Code § 4736(c).

⁴ Va. Code § 54.1-2990.

⁵ This was also a key element of S.B. 439 (2007) (Duell) that was passed by the Senate.

negates the effectiveness of the Section 166.046 which was intended to permit providers to stop providing medically inappropriate treatment.

Because most medical futility disputes are resolved informally, losing the Section 166.046 safe harbor might be thought to have little impact. Consensus is usually reached without using the formal mechanisms provided in the Texas Advance Directives Act. Section 166.046 is primarily for “intractable” medical futility disputes. Since only 5% of such disputes are intractable, the impact of negating Section 166.046 seems limited. Moreover, many of the patients who are the subjects of intractable disputes (for which Section 166.046 was designed) are so catastrophically ill that they die during the duration of the process (48 hours notice for the committee meeting and ten days for the transfer). So, the Section 166.046 procedure makes no practical difference not only for the 95% of disputes resolved informally but also for a significant subset of the remaining 5% (the intractable cases).

Nevertheless, one must be careful not to underestimate the indirect effects of Section 166.046. First, just having a law like this may have an influence on physician-surrogate culture. It may support the increasingly important and valuable message that more technology is not necessarily better. Second, the 95% resolution rate may be aided by Section 166.046, because all parties know their BATNA (Best Alternative to a Negotiated Agreement). In short, without Section 166.046, the current high resolution rate could drop.

5. There Are Alternatives to Section 166.046.

Documented experience in other states indicates that providers are unwilling to refuse life-sustaining medical treatment, if surrogates continue to demand such treatment after mediation. Providers want clear and precise safe harbors. Indeed, other states without a well-defined safe harbor like Texas have been working to copy Texas’ law.⁶ Without clear and precise safe harbors, the fear of (even low-probability) sanctions for withholding and withdrawing life-sustaining treatment without surrogate consent compels providers to accede to surrogate demands.

Nevertheless, there are at least two important alternatives to Section 166.046 through which physicians can refuse inappropriate treatment requests. First, Section 166.045(c) provides an explicit alternative to the Section 166.046 procedures:

If an attending physician refuses to comply with a directive or treatment decision and **does not wish to follow the procedure established under Section 166.046**, life-sustaining treatment shall be provided to the patient, but only until a reasonable opportunity has been afforded for the transfer

⁶ See, e.g., Idaho S.B. 1114 (2009) (passed Senate 34-0-1); California Medical Association Resolution 505-08 (2008).

of the patient to another physician or health care facility willing to comply with the directive or treatment decision.

Even if H.B. 3520 effectively eliminated the Section 166.046 mechanism, providers could still refuse life-sustaining medical care pursuant to Section 166.045. And they would only need to afford a “reasonable opportunity” for transfer.

Nevertheless, Section 166.044 directs that a physician refusing to comply pursuant to Section 166.045(c) must do so consistent with the malpractice standard of care. Again, because compliance with this standard is uncertain, providers would likely be chilled from using Section 166.045(c). In short, Texas providers proceeding under Section 166.045(c) would be in much the same position as providers in other states. In those states it is common for physicians to feel threatened by legal action by the patient’s surrogate, and thus continue to provide such care against their best medical judgment.

A second mechanism by which Texas providers can avoid providing inappropriate medicine is to replace surrogates who demand inappropriate medical treatment for patients. In almost all futility disputes the patient lacks decision making capacity at the time the treatment decision is made. So, the decision is made by a surrogate decision maker – usually a family member. Therefore, the dispute is not really between a patient and a provider but between a surrogate and a provider.

In those medical futility cases that present the most compelling case for the provider’s unilateral refusal of life-sustaining treatment, continued treatment arguably causes suffering to the patient with no corresponding benefit. In these cases the surrogate may not be complying with applicable decision making standards.⁷ Therefore, unless the surrogate can demonstrate that the patient really wanted life-sustaining medical treatment under such circumstances, the surrogate can and should be replaced.⁸

6. Section 166.046 Violates Procedural Due Process.

The Texas Act mechanism is pure process. Providers can stop treatment for any reason, so long as the ethics committee agrees and the surrogate gets the statutorily-mandated notice. There is nothing wrong with pure process mechanisms. It is the best we can do in the face of incommensurable value conflict. But if process is all you have, then it must have integrity and fairness. Section 166.046 does not have enough. Even key proponents of the Advance Directives Act have conceded these defects.⁹

⁷ Tex. Health & Safety Code § 166.152(e) (“[T]he agent shall make a health care decision: (1) according to the agent's knowledge of the principal's wishes, including the principal's religious and moral beliefs; or (2) if the agent does not know the principal's wishes, according to the agent's assessment of the principal's best interests.”).

⁸ Thaddeus Mason Pope, *Surrogate Selection: An Increasingly Viable, but Limited, Solution to Intractable Futility Disputes*, 3 St. Louis J. Health L. & Pol’y 183-252 (2010).

⁹ See, e.g., Thomas Wm. Mayo, *The Baby Doe Rules and Texas’s “Futility Law” in the NICU*, 25 Ga. St. U. L. Rev. 1003 (2009); Texas Hospital Association, *Key Messages on the Texas Advance Directives Act*

Due process includes a classic bundle of rights:

- Notice
- Opportunity to present
- Opportunity to confront
- Assistance of counsel
- Independent, neutral decision maker
- Statement of decision with reasons
- Judicial review

Criminal defendants get all of these. Patients subject to Section 166.046 get almost none of them.¹⁰ To be precise, the statute itself does not afford them. Some hospitals may provide them in practice voluntarily. But many providers treat legal obligations as a ceiling, not as a floor. Providers should give patients what they give themselves: the more elaborate due process used everywhere from peer review involving a restriction of privileges to adverse licensure actions.¹¹

No Neutral Decision Maker. The intramural institutional ethics committee makes the final decision to stop treatment. But the ethics committee is controlled by the hospital. It is not independent. Section 166.046 Act recognizes the need for an “independent” check That’s why it requires ethics committee review. That’s why it prohibits the referring physician from serving on the ethics committee. But this is not enough. The statute gives life-and death decision making power without demanding sufficient (or any) accountability in return.¹²

The Texas Act is totally silent on ethics committee composition. In a 2007 study researchers found that one-half of ethics committees had five or fewer members.¹³ Most

(“[S]ome clarifications in state law may be appropriate to make it easier for families to understand and participate in the decision-making process.”); Robert L. Fine, *Point: The Texas Advance Directives Act Effectively and Ethically Resolves Disputes About Medical Futility*, 136 Chest 963-967 (2009). In 2009, representatives from Seton Healthcare testified that they voluntarily go above and beyond the law’s requirements. For example, they allow attorneys to be present at ethics committee meetings; they have appointed disability advocates to its committees; and they have gone beyond the minimum 10 days. Hearing on H.B. 3325 (2009) (Hughes) before the House State Affairs Committee (April 14, 2009). But there are nearly 600 hospitals in Texas. <http://www.tha.org/GeneralPublic/Hospitals/index.asp>. Many of these do not voluntarily go above the low floor set by the statute.

¹⁰ See, e.g., Nora O’Callaghan, *Dying for Due Process: The Unconstitutional Medical Futility Provision of the Texas Advance Directives Act*, 60 Baylor L. Rev. 527 (2008); Thomas J. Balch, *Are There Checks and Balances on Terminating the Lives of Children with Disabilities? Should There Be?* 25 Ga. St. U. L. Rev. 959 (2009).

¹¹ I have space here to discuss (briefly) only two aspects of due process. Other aspects have been analyzed elsewhere. Many were addressed in S.B. 439 (2007) (Duell).

¹² In contrast, New York’s new Family Health Care Decisions Act (effective June 2010) gives ethics committees some decision making power. But it also thoroughly specifies the composition and operation of those committees. N.Y. Pub. Health L. § 2994-m.

¹³ Martin L. Smith et al., *Texas Hospitals’ Experience with the Texas Advance Directives Act*, 35 Critical Care Med. 1271 (2007).

had ten or fewer members. And they are not very multidisciplinary. There is no “community member” requirement as there is for Institutional Review Boards. Indeed fewer than 10% of Texas ethics committees have a community member. Maybe giving power to an intramural ethics committee did not seem odd in 1999, when the Act was passed. But it sure seems odd today. Over the past decade there has been significant inquiry and discussion of conflict of interest -- from the pharmaceutical and device industries to dramatically expanded fraud and abuse enforcement. There is no doubt that money often sits at the ethics committee table. Money seems to drive some futility cases.¹⁴ And even apart from money, it is hard for ethics committee members to be objective and circumspect.¹⁵

Statement of Decision. The purpose of requiring a statement of decision is to provide a rationale, a factual basis for the decision. It demonstrates that the decision is considered and supported. Admittedly, Section 166.046 does require a statement of decision. But the decisions are of highly variable quality.

For example, in the Emilio Gonzales case Seton Hospital in Austin wrote two careful reports laying out the facts and reasoning. In contrast, in the case of Maurice Davis Memorial Hermann in Houston wrote a brief cover letter stating the committee found life-sustaining treatment “medically inappropriate” for the reasons on the attached documentation. The attached documentation, a pre-printed form, contains only three fields: (1) background, (2) intervention under review, and (3) conclusion. There is no room for reasons, for explanation on why the treatment is inappropriate. And none is provided.

Furthermore, Section 166.046 is silent not only on substantive criteria but also on procedures and methodology. It is silent on everything from quorum and voting requirements to what a written decision must look like or address. The result is highly variable use of the procedures in hospitals across Texas.

7. Conclusion

Section 166.046 outlines a unique approach to resolving intractable medical futility disputes. Indeed, it has been effective in allowing providers to refuse life-sustaining treatment when such treatment is demanded by the surrogate but medically inappropriate for the patient.

H.B. 3520 changes Section 166.046 by dramatically narrowing the circumstances under which providers can refuse inappropriate life-sustaining treatment. Specifically, under H.B. 3520, providers can refuse only after they have transferred the patient to a new provider willing to provide such treatment.

¹⁴ See, e.g., Mimi Swartz, *Not What the Doctor Ordered*, Texas Monthly, Mar. 1995.

¹⁵ See Thaddeus Mason Pope, *Multi-Institutional Healthcare Ethics Committees: the Procedurally Fair Internal Dispute Resolution Mechanism*, 31 Campbell L. Rev. 257-331 (2009).

Section 166.046 is not the exclusive mechanism by which Texas providers may refuse inappropriate life-sustaining treatment. Providers can often replace surrogates who demand aggressive treatment that the patient would not have wanted or that is not in the patient's best interests. But this is not complete solution. Often there will be insufficient evidence of the patient's wishes to demonstrate a contradiction with the surrogate's decision. And, sometimes, the surrogate will faithfully report patient preferences for continued treatment even in the face of suffering or permanent unconsciousness.

The Committee must balance two sets of risks. On the one hand, there is the risk that the lack of safeguards in Section 166.046 will lead to the refusal of life-sustaining treatment on illegitimate grounds. On the other hand, there is the risk that, under a "treat until transfer" rule like that provided in H.B. 3520, patients will be provided non-beneficial treatment. This can result in physical suffering and a loss of dignity to the patient. It can also result in harm to other patients due to the unavailability of ICU beds, increased antibiotic resistance, and the amplified moral distress of healthcare providers.

Based on representations made by key stakeholders during the 2009 session, it appears that a compromise may be possible that avoids both of these extremes. Specifically, enhancing the safeguards and procedural due process protections in Section 166.046 would protect patients from illegitimate refusals. But it would still permit providers to refuse inappropriate treatment.