

# THE BABY DOE RULES AND TEXAS'S "FUTILITY LAW" IN THE NICU

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## I. INTRODUCTION

The applicability of Texas's futility provision in the NICU and its relationship to the Baby Doe rules are reasonably straightforward. Nonetheless, many comments have been written about Texas's so-called "futility law," some of them complimentary and others, not so much. The most serious critiques of the Texas futility provision, however, are based upon assumptions that result from a fundamental misreading of the law. After a brief discussion of the futility provision and its principal features, this Essay will examine the misunderstandings that plague many critiques of the law and then offer a list of proposed amendments to the law that address some of the actual deficiencies in the futility provision.

## II. BACKGROUND

In 1999, Texas lawmakers<sup>1</sup> set out to combine three end-of-life laws into one.<sup>2</sup> The primary goal was to harmonize the three laws by eliminating inconsistencies in the witnessing provisions, adding and sharpening some of the definitions, revising the authorized advance-directive forms, and adopting a consistent and politically acceptable approach to the laws' liability rules.<sup>3</sup>

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1. The legislature was assisted by an advisory panel of which I have been a member since 1998. Opinions offered in this article are mine alone and should not be attributed to other members of the group.

2. The three laws were the Natural Death Act, TEX. HEALTH & SAFETY CODE ANN. ch. 672 (1997); the Out-of-Hospital Do-Not-Resuscitate law, *id.* ch. 674; and the Durable Power of Attorney for Health Care law, TEX. CIV. PRAC. & REMEDY CODE ch. 135 (1997).

3. Opposition to revisions to the liability rules (which replaced negligence with good faith as the liability standard for physicians) helped to derail a similar attempt to harmonize the three laws in 1997. The result was vetoed by then-Governor Bush, *see* Proclamation by the Governor of Texas (June 20,

Early on, the legislature's advisory panel declared all provisions of the three laws—those that were present in the statutes, as well as those that were missing—to be on the table for discussion. Accordingly, members of the advisory panel were encouraged to promote their “wish lists,” subject to the understanding that no new provision would be submitted to the legislature unless it had the full backing of all members of the panel.<sup>4</sup>

The most notable provision to emerge from the 1999 harmonization effort was the provision that dealt with medical-futility disputes, particularly disputes between surrogate decision makers and physicians over treatments deemed by the physicians to be “inappropriate.” Although it is often referred to as the “Texas futility law,” this provision is a single subsection<sup>5</sup>—Section 166.046(e) of the *Texas Health & Safety Code*—of a large and complex matrix of related Sections in which the word “futility” never appears.<sup>6</sup> To understand what Section 166.046(e) does and does not do, it may be helpful to consider how it fits into Section 166.046 (and related provisions of the Texas Advance Directives Act) as a whole.

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1997) (vetoing S.B. 414), at <<http://www.lrl.state.tx.us/scanned/vetoes/75/sb414.pdf#navpanes=0>> (last visited June 23, 2009), who then informally requested that the drafting group take another shot at harmonization in 1999.

4. The panel was a diverse group, including representatives from state agencies responsible for paying for or providing end-of-life treatment, health-care professional and industry associations and advocacy groups, a handful of hospitals, a few individuals, and the Texas Right to Life and National Right to Life Committees. Members of the advisory panel were, of course, free to dissociate themselves from the final product, and keeping the panel together was viewed as essential if the final recommendation was going to be politically viable. Some of the history and a brief description of the 1998–1999 drafting effort are set out in Robert L. Fine & Thomas Wm. Mayo, *Resolution of Futility by Due Process: Early Experience with the Texas Advance Directives Act*, 138 ANNALS INTERNAL MED. 743, 744 (2003).

5. TEX. HEALTH & SAFETY CODE § 166.046 (Vernon Supp. 2001).

6. Because of the well-documented failures of commentators to develop a definition for “medical futility” that could attract general agreement, see, e.g., Paul R. Helft et al., *The Rise and Fall of the Futility Movement*, 343 NEW ENG. J. MED. 293 (2000); Jeffrey P. Burns & Robert D. Truog, *Futility: A Concept in Evolution*, 132 CHEST 1987, 1988–89 (2007) (hereinafter “*Futility: A Concept in Evolution*”), Section 166.046(e) of the Texas Advance Directives Act addresses disputes that arise when patient representatives ask for treatments that are deemed by the attending physician to be “inappropriate,” a term that is arguably broader and certainly no less inscrutable than “futile,” cf. Jeffrey P. Burns & Robert D. Truog, Correspondence, 134 CHEST 888, 888 (2008) (“[‘Inappropriate’] has a commonly understood meaning or agreed-upon definition. The truth is that no such meaning or definition exists.”).

Section 166.046 addresses various types of disagreements over end-of-life decisions, including both "classic right-to-die" cases as well as so-called "futility disputes," sometimes referred to as "reverse right-to-die" (or, less charitably, "duty to die") cases.<sup>7</sup> Both types of disagreements trigger the same set of procedural safeguards under the law.<sup>8</sup> First, a hospital ethics or medical committee<sup>9</sup> must conduct a review of the treatment dispute, with at least forty-eight hours' prior notice to the surrogate decision maker,<sup>10</sup> who is entitled to attend the review session.<sup>11</sup> The hospital is also obligated to provide the surrogate with a detailed "Statement Explaining the Patient's Right to Transfer"<sup>12</sup> and may also provide an additional "written description of the ethics or medical committee review process and any other policies and procedures . . . adopted by the health care facility."<sup>13</sup> Once the review process is over, any decision shall be reduced to writing, which will be given to the surrogate<sup>14</sup> and placed in the patient's medical record.<sup>15</sup> If anyone involved in the process disagrees with the outcome of the ethics committee's review, the physician (with the assistance of the facility's staff) shall try to

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7. The primary difference between the two types of disputes has to do with the identity of the party who demands more care and the party who resists the demand. In a "classic right-to-die" case, the family resists further aggressive treatment and the treating physician argues for its continuation. The cases of Karen Ann Quinlan and Nancy Beth Cruzan are two of the best known of these "classic right-to-die" cases. *In re Quinlan*, 355 A.2d 647, cert. denied, 429 U.S. 922 (N.J. 1976); *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990). In futility cases, it is the patient's representative who demands a level or type of treatment—often with the request that "everything be done" to keep the patient alive—and the physicians who resist on the ground that the requested treatments would not produce a benefit for the patient. One of the earliest such cases involved Helga Wanglie, who was diagnosed in a persistent vegetative state and whose caregivers sought (unsuccessfully) to have her husband replaced as her guardian with someone more likely to consent to the withdrawal of ventilator support. *See Futility: A Concept in Evolution*, *supra* note 6, at 1988.

8. Just as Section 166.046 applies to both types of "right-to-die" disputes, it can be invoked by patients, surrogates, and physicians alike.

9. Most of these disputes are likely to arise in a tertiary- or quaternary-care facility, where there will probably be an in-house ethics committee. If not, another kind of "medical committee" is permitted by the statute. TEX. HEALTH & SAFETY CODE ANN. § 166.046(a) (Vernon Supp. 2001).

10. *Id.* § 166.046(b)(2).

11. *Id.* § 166.046(b)(4)(A).

12. *Id.* §§ 166.046(b)(3)(A), 166.052.

13. *Id.* § 166.046(b)(1).

14. *Id.* § 166.046(b)(4)(B).

15. TEX. HEALTH & SAFETY CODE ANN. § 166.046(c) (Vernon Supp. 2001).

transfer the patient to another physician, an alternative care setting, or another facility where the surrogate's treatment decision can be complied with.<sup>16</sup>

Under Section 166.046(e), a surrogate's demand for "inappropriate" treatment is to be treated just like traditional "right to die" disputes, with the added proviso that if the ethics committee agrees with the physician, life-sustaining treatment shall be continued for at least ten days, during which time the physician and facility shall try to effect the patient's transfer. If no facility or physician is found who will accept the transfer, at the end of the ten-day waiting period, neither the facility nor the physician is obligated to continue to provide life-sustaining treatment. Finally, if all of the required procedures in Section 166.046 are followed, the physician, facility, and any health professional acting under the direction of the physician are immune from civil and criminal liability and disciplinary action by the appropriate licensing board.<sup>17</sup>

From 1999 to 2003, this procedural safe harbor applied (with one slight exception) only to disputes involving adult patients.<sup>18</sup> In 2003 the legislature amended the Advance Directives Act so that Section 166.046 would apply to minor patients as well as adults.<sup>19</sup> At the same time, the legislature added Section 166.010 to the Advance Directives Act to emphasize that the Act was "subject to applicable federal law and regulations relating to child abuse and neglect [*i.e.*, the Baby doe rules] to the extent applicable to the state based on its

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16. *Id.* § 166.046(d).

17. *Id.* § 166.045(d).

18. As originally enacted, Section 166.046 applied when a physician disagreed with an advance directive (including, in theory—but rarely in practice—an advance directive executed on behalf of a minor) or with a treatment decision on behalf of an incompetent *adult* patient without a directive, guardian, or health care agent. S.B. 1260, § 1.03 (1999) (adding § 166.046). This latter limitation resulted from a cross-reference to "a treatment decision under Section 166.039, which authorizes treatment decisions for certain *adult* patients." *Id.*; see also Section 166.039's limited applicability to adult patients.

19. This was done by eliminating Section 166.046's cross-reference to Section 166.039 and reworking the definition of "health care or treatment decision" to make it clear that it "includ[es] such a decision on behalf of a minor." S.B. 1320, §§ 1 (amending definition of "health care or treatment decision"), 4 (eliminating cross-reference in Section 166.046(a) to Section 166.039) (2003).

receipt of federal funds."<sup>20</sup> This provision would appear to add little or nothing to the implicit acknowledgement in the governor's annual certification to the Department of Health and Human Services pursuant to the Baby Doe rules that Texas has procedures for responding to reports of medical neglect, including "the withholding of medically indicated treatment from disabled infants with life-threatening conditions."<sup>21</sup>

Nothing contained in the Advance Directives Act in general, Section 166.046 specifically, or the acknowledgement of Baby Doe's applicability in Section 166.010 changed the impact of the Baby Doe rules on clinical practice in Texas. Before 2003, if Child Protective Services officials believed that medically indicated treatment was being withheld from an infant, they could seek a court order directing the treatment to be provided or designating the state agency as temporary guardian for purposes of making treatment decisions. After the 2003 amendments, the same was true. The Advance Directives Act confers broad legal immunity on physicians, facilities, and health professionals working under the direction of physicians, but it does not purport to make any change in the legal status of, or the rules that are enforced by, Child Protective Services.

### III. THE PRINCIPAL OBJECTION TO THE ADVANCE DIRECTIVES ACT

Two of the most persistent and insightful critics of Section 166.046 are Dr. Robert Truog and Professor Thaddeus Mason Pope. Their core objection is that the 1999 law is procedurally deficient because

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20. S.B. 1320, § 2 (2003) (adding § 166.010 and language quoted in text). The meaning of this provision is somewhat obscure. It may simply recognize the unremarkable proposition (even in Texas!) that federal law applies as long as the precondition for the application of federal law continues to be satisfied. It does not appear to settle the question whether the Baby Doe rules (i) are merely a federal-state funding mechanism for the state's child protective services program or (ii) establish a federal standard of care for disabled infants. Texas courts have been disinclined to see the Baby Doe rules as anything more than a funding mechanism. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 771 (Tex. 2003) (describing the Baby Doe rules as "federal funding regulations" and agreeing with the lower court's conclusion that the question of a hospital's liability for treating a newborn over the objections of her parents "is governed by state law rather than federal funding authorities").

21. 42 U.S.C. § 5106a(b)(2)(B) (2006).

of the absence of minimal due-process safeguards against biased, substantively flawed, or otherwise inappropriate decision-making by treating physicians. In particular, they decry the Advance Directives Act's failure to provide for judicial review and its reliance upon an extrajudicial review mechanism that is implemented by the hospital's ethics committee, which they criticize as staffed by "insiders" whose lack of independence fails to meet even minimum standards of decisional fairness.<sup>22</sup>

The due-process criticism starts off right but ends up seriously wrong. The advisory panel very consciously chose to provide an intramural ethics committee review of "futility disputes" (as well as disputes involving surrogates' refusal of continued treatment). The in-house ethics committee approach offered real advantages over a judicial forum. First, members of the ethics committee bring expertise to the controversy, an expertise that general-jurisdiction trial judges usually lack. Second, the members of the ethics committee may not include physicians with direct patient-care responsibility. There is no particular reason to believe that such a committee would routinely rubber-stamp their physician-colleagues positions in the context of a Section 166.046 review, short of a deep-seated distrust of hospital workers and volunteers. Third, there is little in the training or experience judges receive to reflexively believe that judicial review should be the gold standard for decision-making in end-of-life disputes. To be sure, judges are experts *at due process*, but are they equally expert in the realm of medical decision-making?

One other concern motivated me to prefer an ethics committee review over a judicial one in 1998–1999, and I still find it persuasive

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22. See, e.g., Thaddeus Mason Pope, *Multi-Institutional Healthcare Ethics Committees: The Procedurally Fair Internal Dispute Resolution Mechanism*, 31 CAMPBELL L. REV. 257, 274–99 (2009); Thaddeus Mason Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1, 79–80 (2008); Robert D. Truog, *Tackling Medical Futility in Texas*, 357 NEW ENG. J. MED. 1 (2007); *Futility: A Concept in Evolution*, *supra* note 6, at 1990–91. The substitution of a hospital ethics committee hearing for a judicial one also lies at the heart of Professor Nora O'Callaghan's critique of Section 166.046, see Nora O'Callaghan, *Dying for Due Process: The Unconstitutional Futility Provisions of the Texas Advance Directives Act*, 60 BAYLOR L. REV. 625 (2008), although Professor O'Callaghan's criticisms go considerably further than the realm of due-process.

today. As far back as the first state supreme court's decision in a "right to die" case—that of the New Jersey Supreme Court in *In re Quinlan*<sup>23</sup>—there has been a recognition that the possibility of legal liability may weigh heavily on the physician on whose objective judgment everyone involved in the patient's care should have the right to rely.<sup>24</sup> Without some measure of protection, physicians might seriously consider adopting one or more dispute-avoidance strategies. One strategy involves passively going along with everything the surrogate decision maker asks for. This represents an abdication of responsibility (under the guise of "respect for autonomy") and is not necessarily in the best interests of the patient or anyone else. A second dispute-avoidance strategy would be to implement the physician's own preferred treatment plan without consultation with the family or others with a significant role to play: no disclosure and discussion of treatment alternatives, no informed consent, no transparency, and no accountability. In many cases this strategy would need to be implemented discretely, perhaps by undertreating an acquired infection or simply not offering a third or fourth life-sustaining intervention in the face of the latest adverse event for a patient experiencing multi-system organ failure. Neither of these approaches is what most people would consider optimal medical care, but both would avoid the adverse publicity, bad feelings, depositions, and time in court that are entailed by judicial review. It is not hard to

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23. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

24. *Id.* at 668. The New Jersey Supreme Court seemed to express some concern about the "fear of personal retaliation" on physicians' "independent objectivity," as well as the court's desire that "physicians, in the pursuit of their healing vocation, [be freed] from possible contamination by self-interest or self-protection concerns which would inhibit their independent medical judgment for the benefit of their dying patients." *Id.* at 668. In virtually the same breath, the court expressed its reluctance to confer the same type of immunity on physicians in end-of-life disputes as is enjoyed by judges and grand jurors. *Id.* Professor O'Callaghan picks up on the court's reluctance in her critique of Section 166.046, *see* Nora O'Callaghan, *supra* note 22, at 574, but she completely misconstrues the New Jersey Supreme Court's ultimate message. The court went on to say that some type of review of physician decision-making in end-of-life cases would be useful "in screening out, so to speak, a case which might be contaminated by less than worthy motivations of family of physician." *Quinlan*, 355 A.2d 670. But contrary to Professor O'Callaghan's implication, the court favored the routine use of multi-disciplinary ethics committees rather than "applying to a court to confirm such decisions[, which] would generally be inappropriate not only because that would be a gratuitous encroachment upon the medical profession's field of competence, but because it would be impossibly cumbersome." *Id.*

imagine why a physician, whose own judgments and actions control both dispute-avoidance strategies, might view one or the other to be preferable to litigation. With this in mind, Section 166.046(a)'s review by an interdisciplinary ethics committee tries to steer a course between the Scylla of judicial review and the Charybdis of unfettered, unexamined physician discretion.

More fundamentally, however, the critics of Section 166.046 seem to have gotten wrong the whole matter of the availability of judicial review. Put simply, Section 166.046 does not preclude resort to the courts by families that are motivated to seek judicial review.<sup>25</sup>

To be sure, there is nothing in Section 166.046 that explicitly provides for judicial review.<sup>26</sup> During the advisory panel's discussions in 1998 and 1999, however, there was widespread agreement that judicial review would be available, if desired, through the usual routes by which declaratory judgments and injunctions are obtained in Texas. The panel considered spelling out the process in the Advance Directives Act, but rejected that option as unnecessarily redundant.<sup>27</sup> The panel's preference for an extrajudicial forum for the review of end-of-life disputes, however, does not imply a complete rejection of judicial review if that is desired. The New

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25. I offer the following interpretation of the availability of judicial review based upon my reading of the Advance Directives Act as it is written and not out of a belief that formal judicial review is or ought to be required as a normative matter. Apart from the serious "state action" objection to any due-process analysis (at least with respect to private hospitals), even if due-process principles applied to the statutory scheme, state legislatures have the option of providing a reasonable alternative to full-blown judicial review. The Advance Directive Act's scheme—independent review by a multidisciplinary hospital ethics committee with judicial review that ensures that the procedural requirements of the law have been satisfied—is just such a reasonable alternative to full-blown judicial review in most cases.

26. One provision of the Advance Directives Act provides that family members who disagree with a surrogate treatment decision on behalf of an incompetent patient with no advance directive may apply for temporary guardianship under the Texas Probate Code. TEX. HEALTH & SAFETY CODE ANN. § 166.039(g) (Vernon Supp. 2001). A second provision authorizes certain persons to commence an action to request that a medical power of attorney be revoked because of undue influence or the principal was incompetent at the time the medical power of attorney was executed. *Id.* § 166.165. A third provision deals with requests to extend the 10-day waiting period provided by Section 166.046(d). *See infra* note 29. It would be an unwarranted inference from the presence of this judicial-review language that judicial review is precluded because of the absence of such express language in Section 166.046.

27. Some members of the advisory panel may also have wanted to avoid encouraging judicial review by spelling out the process in the Advance Directives Act, thus defeating the preferred extrajudicial review mechanism that was at the heart of Section 166.046.

Jersey Supreme Court in the *Quinlan* case made exactly the same point after it announced its preference for ethics committee review in end-of-life disputes: "[t]his is not to say that in the case of an otherwise justiciable controversy access to the courts would be foreclosed; we speak rather of a general practice and procedure."<sup>28</sup>

There is, of course, language in Section 166.046 that limits the grounds on which a trial court may extend the ten-day waiting period provided by Section 166.046(e),<sup>29</sup> and Section 166.045(d) confers immunity upon "[a] physician, health professional working under the direction of a physician, or health care facility . . . if the person has complied with the procedures outlined in Section 166.046."<sup>30</sup> There are a number of good reasons to decline to read these provisions as precluding judicial review of disputes under Section 166.046.

As a threshold matter, any arguable limitation on a district court's jurisdiction to entertain a lawsuit must depend upon a determination that the statute in which the alleged limitation appears applies to the parties and their dispute. In the context of the Advance Directives Act, this means that a court could only find its jurisdiction to be limited if it first found that the dispute was governed by the Advance Directives Act. In the case of the Act's generic immunity provision,<sup>31</sup> the Act (and its immunities and limitations, if any, on trial court jurisdiction) would not apply if the court found that the physician or health care facility failed "to exercise reasonable care" when applying the patient's advance directive. Various other provisions of the Advance Directives Act invoke the standard of "reasonable medical judgment"<sup>32</sup> or "the prevailing standard of medical care."<sup>33</sup> In like fashion, if a court found one or more of these standard-of-care provisions to have been violated, there would presumably be no

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28. *Quinlan*, 355 A.2d at 670.

29. TEX. HEALTH & SAFETY CODE ANN. § 166.046(g) (Vernon Supp. 2001) (requiring court to find, "by a preponderance of the evidence, that there is a reasonable expectation that a physician or health care facility that will honor the patient's directive will be found if the time extension is granted").

30. *Id.* § 166.045(d).

31. *Id.* § 166.044.

32. *E.g., id.* §§ 166.002(4), (8), (10), (13), 166.033, 166.052.

33. *E.g., id.* §§ 166.002(9), (13), 166.033.

warrant to apply the immunity provision or the limitation on the court's power to extend the ten-day period. In brief, if the Advance Directive Act's substantive and procedural requirements have not been satisfied, the end-of-life dispute is outside the Act.<sup>34</sup> At a minimum, a reviewing court would need to conduct some sort of substantive review in a case that challenged the substance of the physician's position, to determine whether the immunities applied, and the same should be true of the alleged limitation on judicial review itself.

Also, notwithstanding any limitation on the court's power to extend the ten-day waiting period, Texas courts undoubtedly have inherent jurisdiction to preserve the status quo while they explore the existence of their own jurisdiction.<sup>35</sup> Thus, most courts that have been confronted with a dispute under Section 166.046 have not hesitated to issue a temporary injunction until the issues—including the existence of a cause of action and subject-matter jurisdiction—could be sorted out.

Finally, it is highly unlikely that a trial judge would allow a patient to die in a contested case without first exploring the merits of the parties' positions. Similarly, it is equally unlikely that a hospital, once it has been drawn into a judicial-review proceeding, would insist on the strict application of the ten-day waiting period and discontinue life-sustaining treatment while the case was *pendente lite*. The ten-day limit, after all, ends with *permission* to discontinue life-sustaining treatment, not a command to do so. Unless a strong case could be made that continued treatment was the literal equivalent of torture—a rarity, to be sure—the hospital would be ill-advised to

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34. This argument is a little harder, but not impossible, to make with respect to the immunity provision that applies solely to disputes under Section 166.046. Neither the immunity provision, *id.* § 166.045(d), nor § 166.046 itself contains a standard-of-care provision. It would make very little sense, however, to apply the immunities to an end-of-life dispute under Section 144.046 when the physician's judgment is wildly outside the standard of care, considering how liberally that standard is festooned throughout other parts of the Advance Directives Act. (This should be a rare event, however, if the ethics committee conducts a competent review.) If Texas courts refused to read standard-of-care requirement into Section 166.046, I would certainly support an amendment that made such a requirement explicit.

35. *See, e.g., Dolenz v. Vail*, 200 S.W.3d 338 (Tex. App. 2006).

discontinue life-sustaining treatment before the court had an opportunity to address the merits of the surrogate decision maker's petition.

#### IV. PROPOSED AMENDMENTS

Experience with the Advance Directives Act and service on six hospital ethics committees during the past ten years, as well as the well-considered suggestions of both critics and supporters of the law, suggest that a number of amendments would make the law work more effectively, more ethically, and more fairly. What follows is a brief list of suggested amendments and brief explanations in support of them.<sup>36</sup>

**Judicial review.** As the discussion in the previous Part makes clear, a reasonable reading of the Advance Directives Act would not preclude substantive judicial review, at least in cases where a plausible case can be made that the physician's judgments or actions fall below a reasonable standard of care. If it were necessary to preserve the essential structure of the law, including Section 166.046, from a finding of unconstitutionality, the availability of judicial review could be made more explicit. As a starting point, "reasonable medical judgment" could be added to Section 166.046, so that its express language was brought into line with other parts of the Advance Directives Act and provided a basis for substantive review of the medical decision-making involved in the case. If something more explicit were necessary, the change should be made. Nothing, in my view, would be lost by making more explicit a judicial-review rule that is already latent in the Act.<sup>37</sup>

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36. Any number of other amendments—some technical, others more substantive—should be considered. The Advance Directives Act is the proverbial result of sausage-making at its most extreme, and in its current form, it represents the best that could have been coaxed out of a very diverse advisory panel made up of individuals with quite different agendas. What follows is my list of the changes that deserve the most urgent consideration.

37. I continue to believe, however, that the existing statutory scheme meets the requirements of due process and that the operation of the Act would not be improved by more frequent resort to the courts. See *supra* note 25.

**Limit the scope of the immunity available under Section 166.046.** If there is doubt about the availability of judicial review in cases in which Section 166.046 is invoked, the broad immunity of Section 166.045(d) is one of the principal reasons for that doubt. The immunity from criminal liability should be preserved, as should the immunity from disciplinary action by appropriate licensing boards, but the immunity from civil liability could be limited to monetary damages, making it clear that injunctive relief would still be available as a remedy.

**Limit the scope of Section 166.046.** The Advance Directives Act was never designed to provide a process or an answer for all end-of-life treatment decisions and disputes, let alone all “futility disputes.” Instead, the statute was intended to provide some level of protection for providers in those “core” cases in which public policy recognized a need for a legislative solution.<sup>38</sup> Section 166.046 applies to end-of-life disputes regardless of whether the patient is competent or incompetent, and regardless of whether the patient has an irreversible or terminal condition. In practice, I am aware of only one (nonjudicial) case in which the “inappropriate treatment” provision of Section 166.046 was invoked to overrule the treatment decision of a patient who had decision-making capacity. Although competent patients are theoretically just as capable of demanding inappropriate treatment as surrogate decision makers, the latter are the source of conflict with physicians in the overwhelming majority of cases. The law should be limited to apply only when the patient lacks decision-making capacity. There is good reason to push disputes with competent patients outside the protective ambit of Sections 166.045(d) and 166.046, not least because competent patients should enjoy a presumption of knowing best what they want for themselves in the way of end-of-life care. Their wishes should be overruled only in the most extreme cases, if at all, and these are cases in which the

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38. This is presumably the reason that the Advance Directives Act (as well as its predecessor statute) made it clear that nothing in the Act “impair[s] or supersede[s] any legal right or responsibility a person may have to effect the withholding or withdrawal of life-sustaining treatment in a lawful manner . . . .” TEX. HEALTH & SAFETY CODE ANN. § 166.048 (Vernon Supp. 2001). *See also id.* §§ 166.100, 166.166.

broad statutory immunity of Sections 166.045(d) and 166.046 should not be needed to ensure that the individuals and health care facilities involved are not subject to legal liability.

In addition, Section 166.046 should be limited to disputes over treatment decisions for "qualified patients"—that is, to patients who have been certified to have a terminal or irreversible condition.<sup>39</sup> If limited even further so that the law applied only to patients with terminal conditions, the law would pose little of the risk of discrimination about which disability advocacy groups have publicly worried. If there are patients with irreversible conditions who need to be protected against the overly aggressive treatment choices of their surrogates, the case should be made for extending Section 166.046 to them as well.

**Require a prior informal dispute-resolution-style ethics consultation.** Section 166.046 literally allows for the invocation of the statutory process described in that Section without any prior attempt to resolve the dispute. Many Texas hospitals seem to have gravitated toward a two-step process, even though it is not required by the statute. It should be required of all hospitals, however, as a "best practice" that would give all parties a chance to find an acceptable middle ground without going directly to the formal statutory process. The statutory process does provide an opportunity to resolve the disagreement, but it is not as well suited to that purpose as an informal ethics consultation would be.<sup>40</sup>

**Extend the time deadlines in Section 166.046.** Current law guarantees surrogates at least forty-eight hours' advance notice of the ethics committee review<sup>41</sup> and a minimum of ten days of post-review life-sustaining treatment while the physician and health care facility

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39. *Id.* § 166.031(2).

40. It might also be possible to write into Section 166.046 certain minimum requirements for ethics committees and their members. I am not hopeful that an attempt to "statutorify" ethics committees' membership and processes would be successful, but the effort has a chance to address concerns that many ethics committees are not sufficiently trained or attuned to their role to provide independent and professional review in end-of-life disputes.

41. TEX. HEALTH & SAFETY CODE ANN. §166.046(b)(2) (Vernon Supp. 2001).

attempt to transfer the patient to a willing provider.<sup>42</sup> These timelines have been criticized as too short to provide families with a realistic opportunity to prepare for the review consult or a fair chance to identify a willing provider. These criticisms fail to take into account the days or weeks before Section 166.046 is invoked that most hospitals have spent attempting to arrange for a transfer. The statutory minimums, however, may in some cases be too short to be workable for some families. The time limits could easily be extended to provide a minimum number of weekdays' (rather than calendar days') notice before the review consult occurs (five) or during which the attempt to transfer shall take place (ten). At a minimum, the law should encourage facilities to be flexible in applying the time requirements of Section 166.046 in order to meet the reasonable needs of families and to avoid treating minimum time requirements as setting upper limits.

**Require hospitals to offer another informal dispute-resolution-style ethics consult after the expiration of the ten-day waiting period.** The ten-day waiting period may develop potentially significant information, even if no transfer has been arranged. The patient's condition may have changed, or it may have stayed the same. Treatment alternatives may have been tried with various outcomes. And the fact that no provider has been found who is willing to accept the transfer is a significant fact in itself. Any or all of this new information might contribute to an agreed-upon resolution of the end-of-life treatment dispute. A follow-up ethics consultation should be considered a "best practice" unless it is rejected by the surrogate decision maker.

## V. CONCLUSION

Unilateral withdrawal of life-sustaining treatment should not be done casually and should never be a first resort to settle end-of-life treatment disputes. Proper regard for the values of the patient and the

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42. *Id.* § 166.046(e).

choices of the surrogate decision maker should ordinarily counsel a slow process that ends in unilateral action only as a last resort.

There are, however, cases in which unilateral withdrawal of life-sustaining treatment is the only course that keeps faith with the duty to do no harm. When that is the case, the due-process safe harbor offered by the Texas Advance Directives Act is a reasonable legislative attempt to balance all of the interests of the various parties without sacrificing basic tenets of patient care. Due process values, including substantive judicial review, are more available under the Act than many critics have assumed, but there are still ways for the law to be improved for the benefit of patients, family decision makers, and health care providers.

