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## Surrogate Selection: An Increasingly Viable, But Limited, Solution to Intractable Futility Disputes

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## SURROGATE SELECTION: AN INCREASINGLY VIABLE, BUT LIMITED, SOLUTION TO INTRACTABLE FUTILITY DISPUTES

THADDEUS MASON POPE\*

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## INTRODUCTION

In 2009, the *New England Journal of Medicine* published a very popular interactive clinical case discussion:<sup>1</sup>

A 56-year-old homeless man was found having a seizure and was transported to the hospital.<sup>2</sup> He was found to have a subarachnoid hemorrhage and acute hydrocephalus. He underwent intubation, and mechanical ventilation was started. A shunt was placed to relieve the hydrocephalus; cerebral angiography revealed a ruptured aneurysm of the anterior communicating cerebral artery and an un-ruptured aneurysm of the posterior cerebral artery . . . . The patient's condition did not improve over the next 3 days, and both the neurologist and the neurosurgeon opined that he had a chance of approximately 80 to 90% of being in a long-term persistent vegetative state and only a chance of 5 to 10% of any recovery. His prognosis, at best, was to have a severe disability that would leave him dependent on care by others.<sup>3</sup>

The patient had not been in contact with his family for several years. He had a son who, under the law of the state, was the legal next of kin for making medical decisions if the patient was unable to do so himself.<sup>4</sup> The patient also had a brother and a mother; all three relatives lived 1500 miles away. They were contacted and told of the patient's situation. They were all in agreement that the patient would not want to live in a state in which he would be largely dependent on others for daily care and would have severely impaired cognition. However, the son described the patient as "a fighter" who would want aggressive care until the prognosis was much more certain.<sup>5</sup>

Supportive care, including mechanical ventilation, was continued for the next 3 weeks, without any clinically significant change in the patient's neurologic state. During this time it was discovered that the patient had a very close relationship with a counselor at a homeless shelter with whom he had talked at least every couple of weeks. The counselor came to see the patient and related that the patient had told him that he wished to avoid

1. Arthur S. Slutsky & Leonard D. Hudson, *Care of an Unresponsive Patient with a Poor Prognosis*, 360 NEW ENG. J. MED. 527, 527 (2009). See also Patricia A. Kritek et al., *Care of an Unresponsive Patient with a Poor Prognosis—Polling Results*, 360 NEW ENG. J. MED. e15, e15 (2009).

2. Slutsky & Hudson, *supra* note 1, at 527.

3. *Id.*

4. This article uses the term "surrogate" as a generic term for all substitute decision makers, whether they obtained their authority from patient appointment (e.g., agent, attorney-in-fact, healthcare representative), physician appointment (e.g., proxy), or court appointment (e.g., guardian, conservator). See ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* § 3.04 (3d ed. Supp. 2010) [hereinafter *RIGHT TO DIE*]; see also *supra* notes 19 to 139 and accompanying text.

5. *Id.*

hospitals and that “when his time came” he wanted no aggressive medical care . . . .<sup>6</sup>

Given the lack of improvement in the patient’s neurologic state, the extremely poor prognosis for any meaningful recovery of cognitive function, and the [subsequently-discovered] high probability of cancer, the care team strongly believed that all aggressive and supportive measures should be discontinued and the goals of care changed to those of providing comfort. The brother and mother, who had been quick to respond to queries from the beginning, agreed with the shift to comfort care. However, the son . . . disagreed. He had hardened his position, wanting full aggressive-care measures to be taken, including clipping of the aneurysm.<sup>7</sup>

This is a futility dispute.<sup>8</sup> The patient’s healthcare provider believed that the only appropriate treatment was comfort care. But the patient’s surrogate refused to consent to this recommendation, and instead demanded treatments that, in the providers’ judgment, would cause more harm than benefit. This sort of conflict regularly occurs in hospitals and other healthcare facilities.<sup>9</sup> In the *New England Journal of Medicine* case, it is unclear whether the providers’ conflict with the surrogate was intractable. Consequently, many participants in the online poll rightly voted that an ethics consultation was appropriate.<sup>10</sup> After all, most such disputes are resolved through further communication and mediation.<sup>11</sup>

The focus of this Article is on the avenues for resolution, if the futility dispute proves to be intractable. Many *New England Journal of Medicine* poll respondents wanted to simply override the son, but noted that they would not do so because of legal concerns.<sup>12</sup> Physicians are overwhelmingly reluctant to withhold or withdraw treatment without the

6. *Id.*

7. *Id.*

8. See generally K. Francis Lee, *Postoperative Futile Care: Stopping the Train When the Family Says “Keep Going”*, 15 THORACIC SURGERY CLINICS 481, 481 (2005) (discussing the definition of futile care).

9. See discussion *infra* Part I.B (discussing the prevalence of futility disputes).

10. See Kritek et al., *supra* note 1, at e15.

11. See Thaddeus M. Pope & Ellen A. Waldman, *Mediation at the End of Life: Getting Beyond the Limits of the Talking Cure*, 23 OHIO ST. J. ON DISP. RESOL. 143, 149, 156-57 (2007) (stating, “Mediation looked like the magic Band-Aid to solve end-of-life conflicts.” However, in a growing number of cases further communication results in the provider backing down and the surrogate getting the treatment that he wants.); Sandra H. Johnson et al., *Legal and Institutional Policy Responses to Medical Futility*, 30 J. HEALTH & HOSP. L. 21, 31 (1997) (explaining that the results of a Life Sustaining Treatment Survey showed that futility policies “generally envision[] a primarily consultative, consensus-building approach, rather than an adjudicative or decision making approach”).

12. See Kritek et al., *supra* note 1, at e15-e16.

consent of the authorized decision maker.<sup>13</sup> Accordingly, without explicit permission to do otherwise, physicians generally comply with surrogate requests for treatment even when they think it is cruel and wrong.<sup>14</sup>

Only under Texas law do physicians have clear permission to refuse to provide inappropriate treatment.<sup>15</sup> When providers and patients' surrogates cannot agree on appropriate life-sustaining medical treatment ("LSMT"), the Texas Advance Directives Act ("TADA") designates the hospital ethics committee as adjudicator of last resort.<sup>16</sup> If the hospital committee agrees that the requested treatment is inappropriate, the provider earns legal immunity for refusing to provide it.<sup>17</sup> The Idaho State Senate recently passed a bill to do the same thing.<sup>18</sup> And policymakers in other states have considered, or are now considering, similar legislation, albeit most are vaguer than TADA.<sup>19</sup>

13. See Pope & Waldman, *supra* note 11, at 181-84.

14. See *id.* at 159-61 (citing sources providing physicians' reasons for continuing futile treatment). See also ALISON BARNES, A. FRANK JOHNS & NATHALIE MARTIN, COUNSELING OLDER CLIENTS 317 (2d ed. 2005); JOAN M. KRAUSKOPF ET AL., ELDER LAW: ADVOCACY FOR THE AGING 501 (2d ed. 1993) ("[A] doctor usually will accede to the wishes of a family that insists that care be continued, even if the doctor believes that no benefit is being conferred . . ."); Robert Sibbald, James Downar & Laura Hawryluck, *Perceptions of "Futile Care" Among Caregivers in Intensive Care Units*, 177 CANADIAN MED. ASS'N J. 1201, 1203 (2007) (finding that providers followed the instructions of surrogates instead of doing what they felt was appropriate because of a "lack of legal support.").

15. TEX. HEALTH & SAFETY CODE ANN. §§ 166.045(d), 166.046(a) (West 1999).

16. TEX. HEALTH & SAFETY CODE ANN. § 166.046(a) (West 1999). See generally Robert L. Fine, *The Texas Advance Directives Act of 1999: Politics and Reality*, 13 HEALTHCARE ETHICS COMMITTEE F. 59, 68 (2001) (discussing the purpose of the Texas Advance Directives Act of 1999); Thaddeus Mason Pope, *Legal Briefing: Medical Futility and Assisted Suicide*, 20 J. CLINICAL ETHICS 274, 275 (2009) [hereinafter Pope 2009] (discussing the multi-stage review process).

17. TEX. HEALTH & SAFETY CODE ANN. § 166.045(d) (West 1999).

18. S. 1114, 60th Leg., 1st Reg. Sess. § 5(7) (Idaho 2009).

19. Thaddeus Mason Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1, 54, 58 (2007) [hereinafter Pope 2007] (As of 2007, New Mexico, Maine, Delaware, Alabama, Mississippi, California, Hawaii, Tennessee, Alaska, and Wyoming have adopted the Uniform Health Care Decisions Act, which "has provisions specifically designed to handle futility disputes.") See also Fine, *supra* note 16, at 59 ("Every state has developed laws regulating end-of-life decisions, including various forms for advance directives."); Pope 2007, *supra* note 19, at 53-54, 62-64 (examining notable unilateral decision statutes); Monica Sethi, *A Patient's Right to Direct Own Health Care vs. a Physician's Right to Decline to Provide Treatment*, 29 BIFOCAL 21, 27 (2007) ("All but five states acknowledge a provider's right to refuse to comply with a patient's request for treatment."). The medical societies in several states have been pushing for TADA-type legislation. See, e.g., California Medical Association House of Delegates, Resolutions 505-08 & 506-09; Washington State Medical Association House of Delegates, Resolution C-5 (A-09). See also *Betancourt v. Trinitas Hospital*, No. A-003849-08T2 (N.J. Sup. Ct., App. Div. Aug.

But Harvard Medical School Professor Robert Truog argues that this too-provider-friendly sort of internal dispute resolution legislation is both unnecessary and dangerous.<sup>20</sup> He argues that current healthcare decision laws in every state *already* give healthcare providers an adequate mechanism to avoid providing inappropriate medicine demanded by surrogates. Specifically, when a surrogate demands treatment that providers deem medically inappropriate, these “surrogate selection” laws often permit (or even encourage) providers to designate a different new surrogate from whom consent to withhold/withdraw can be obtained.<sup>21</sup>

7, 2009) (Amicus brief of Medical Society of New Jersey and New Jersey Hospital Association asking an appellate court to adopt a TADA-type process).

20. See Jeffrey P. Burns & Robert D. Truog, *Futility: A Concept in Evolution*, 132 CHEST 1987, 1991 (2007) (expressing concern that TADA “gives an unwarranted amount of power to the clinicians and hospitals over patients and families who hold unpopular beliefs or values”); Robert D. Truog, *Counterpoint: The Texas Advance Directives Act Is Ethically Flawed: Medical Futility Disputes Must Be Resolved by a Fair Process*, 136 CHEST 968, 969 (2009) [hereinafter Truog, *Counterpoint*] (suggesting that TADA’s placement of the life-and-death decision in the hands of hospital ethics committees is too-provider friendly because “[m]ost of these committee members are doctors, nurses, and other clinicians from the hospital community . . . [thus] involvement of the hospital ethics committee fails to bring the diversity of the community into the deliberative process”); Robert D. Truog, *Medical Futility*, 25 GA. ST. U. L. REV. 985, 1000, 1002 (2009) [hereinafter Truog, *Medical Futility*] (criticizing TADA’s due process approach as “more illusory than real” and suggesting that the internal dispute resolution is unnecessary); Robert D. Truog, *Rebuttal from Dr. Truog*, 136 CHEST 972, 972-73 (2009) (suggesting that TADA is unnecessary and that ethics committees should not have unchecked decision-making power); Robert D. Truog, *Tackling Medical Futility in Texas*, 357 NEW ENG. J. MED. 1, 3 (2007) [hereinafter Truog 2007] (stating that internal dispute resolution in Texas is both unnecessary and runs the risk of “becoming a rubber-stamp mechanism” that does not respect diversity). This article focuses on Truog’s argument that unilateral refusal legislation is unnecessary. *Id.* For a fuller explication on why such legislation might be dangerous, see Thaddeus Mason Pope, *Multi-Institutional Healthcare Ethics Committees: The Procedurally Fair Internal Dispute Resolution Mechanism*, 31 CAMPBELL L. REV. 257, 258 (2009) (expressing concern that healthcare ethics committees make treatment “decisions that suffer from risks of corruption, bias, carelessness, and arbitrariness”).

21. This is my term, not Truog’s; but the concept is the same. See Burns & Truog, *supra* note 20, at 1989, 1991-92 (discussing the procedure used by hospitals to have the court appoint an alternate decision maker and how that procedural approach has been translated into state law); Pope, *supra* note 19, at 23-24 (stating that if “the health care provider . . . doubt[s] that the surrogate’s decision reflects the patient’s actual preferences or best interests . . . providers may try to switch the legally authorized decision maker to one that will agree with their recommendation to cease LSMT”); Robert D. Truog, *Correspondence, Tackling Medical Futility in Texas*, 357 NEW ENG. J. MED. 1558, 1559 (2007) [hereinafter Truog, *Correspondence*] (responding to criticism in a letter to the journal editor by arguing for “existing pathways to challenge the legitimacy of the surrogate to make these decisions and to seek appointment of another decision maker”). See also Rasa Gustaitis, *Right to Refuse Life-Sustaining Treatment*, 81 PEDIATRICS 317, 318, 321 (1988) (suggesting the use of child abuse laws to override parental requests for inappropriate treatment).

Truog argues that a mechanism like TADA is most useful, and most justified, when surrogates make decisions not in the best interests of patients. But in precisely such a situation, there is no need to resort to a TADA-type mechanism. Instead, Truog argues, the “remedy should be to use existing pathways to challenge the legitimacy of the surrogate to make these decisions and to seek appointment of another decision maker.”<sup>22</sup>

The logic behind these “surrogate selection” laws is simple. A surrogate is the patient’s agent and, as such, must act according to the patient’s instructions, known preferences, and best interests. When a surrogate exceeds the scope of her authority, she can and should be replaced.<sup>23</sup> For example, providers took a surrogate selection approach in the famous *Helga Wanglie* case.<sup>24</sup> Instead of asking the court to directly determine that their recommended treatment was correct, providers instead asked the court only to make a procedural decision appointing a new surrogate.<sup>25</sup> This surrogate, in turn, would make the substantive decision (presumably in accordance with provider recommendations).<sup>26</sup>

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22. Truog, Correspondence, *supra* note 21, at 1559. See also Truog, *Counterpoint*, *supra* note 20, at 969 (declaring “I think a better approach would be for clinicians to be more proactive in legally challenging the decisional authority of the surrogates”); Truog, *Medical Futility*, *supra* note 20, at 995 (“When family members insist upon treatments that are causing pain or suffering, we need to be much more proactive in challenging their role as surrogate decision makers, and we need to seek to have them replaced . . .”); Robert D. Truog, *Futile Care Debate and Baby Doe: Resolving Difficult Cases When Further Treatment May Be Considered Futile*, Georgia State University College of Law Baby Doe Symposium: The 25th Anniversary of the Baby Doe Rules: Perspectives from the Fields of Law, Health Care, Ethics, and Disability Policy (Feb. 13, 2009), [http://law.gsu.edu/lawreview/index/symposium/spring\\_2009/videos](http://law.gsu.edu/lawreview/index/symposium/spring_2009/videos). Even one of TADA’s authors admits that much of the motivation for unilateral refusal stems from distrust of surrogates. Thomas Wm. Mayo, *The Baby Doe Rules and Texas’ ‘Futility Law’ in the ICU*, 25 GA. ST. U. L. REV. 1003, 1013 (2009). But cf. Robert L. Schwartz, *Autonomy, Futility, and the Limits of Medicine*, 1 CAMBRIDGE Q. HEALTHCARE ETHICS 159, 161-62 (1992) (arguing that the question of whether Mr. Wanglie was his wife’s best substitute decision-maker was the “wrong question,” and “[t]he real question [should have been] whether the continuation of ventilator support and gastrostomy feeding were among the reasonable medical alternatives that should have been available to Mrs. Wanglie or her surrogate decision maker, whoever that might be”).

23. See Peter B. Terry, *Informed Consent in Clinical Medicine*, 131 CHEST 563, 565 (2007) (“Occasionally, the legal surrogate does not act in the patient’s best interest . . . In such instances, the physician must ensure . . . that someone who will act in the patient’s best interest is named.”).

24. *In re: The Conservatorship of Helga M. Wanglie*, 7 ISSUES L. & MED. 369 (1991) [hereinafter *In re Wanglie*].

25. *Id.* at 371, 376.

26. See *id.* at 371 (stating that the physician nominated a conservator to replace Helga Wanglie’s husband as her surrogate).



In Section One, I describe the nature and prevalence of futility disputes. In Section Two, I describe the role of surrogates and the standards that they must apply when making medical treatment decisions on behalf of patients. Unfortunately, the available empirical evidence indicates that surrogates do a rather poor job of representing patient's preferences and interests. So, in Section Three, I argue that unfaithful surrogates should be replaced.

In Section Four, I demonstrate that surrogate replacement is a proven and viable dispute resolution mechanism. While providers were ultimately unsuccessful in both *Wanglie* and similar cases during the early 1990s, surrogate selection has, more recently, proven to be a successful approach. Emblematic of this trend is a string of cases during 2008 and 2009 in which several courts replaced patients' surrogates because they were demanding inappropriately aggressive end-of-life treatment.<sup>27</sup>

Finally, in Section Five, I argue that while surrogate selection has become increasingly well grounded both in statutory standards and in judicial precedent, it remains only a *partial* solution to intractable futility disputes. To replace a surrogate requires evidence of a contradiction between the surrogate's decision and the patient's instructions, known preferences, or best interests. But, for two main reasons, providers will frequently be unable to demonstrate any such contradiction. First, providers will often lack enough evidence of patient instructions or preferences to demonstrate surrogate deviation. Second, in many cases, surrogate decisions will actually be in harmony with patient wishes.

In sum, Professor Truog is right to endorse surrogate selection as a solution to intractable futility disputes. It is a mechanism that can work, and one that, where possible, should be preferred over power-shifting laws. Yet, since surrogate selection cannot resolve significant categories of conflict, we must still develop dispute resolution mechanisms to handle those remaining disputes in which providers conflict with "irreplaceable" surrogates.

#### I. THE NATURE AND PREVALENCE OF MEDICAL FUTILITY DISPUTES

Before turning to the role of the surrogate in Section II, it is useful to first establish some basic features of a medical futility dispute. In this Section, I shall briefly consider: (a) the nature and causes of medical futility disputes, (b) the prevalence of such disputes, and (c) the high rate of informal collaborative resolution.

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27. See *infra* notes 278-387 and accompanying text.

### A. *What Is a Medical Futility Dispute?*

A medical futility dispute arises when a provider seeks to stop treatment that the patient or surrogate wants continued.<sup>28</sup> The provider judges life-sustaining medical treatment to be of no benefit and wants to “stop the train” when the patient or surrogate says, “Keep going!”<sup>29</sup> The provider wants to stop LSMT even without consent of the patient or surrogate. Accordingly, a medical futility dispute is sometimes referred to as a “reverse end-of-life,”<sup>30</sup> a “right to live” or “right to life,”<sup>31</sup> a “right to die” or “duty to die,”<sup>32</sup> or even an “involuntary euthanasia”<sup>33</sup> situation.

One recent futility case was presented to the Court of Queen’s Bench of Alberta.<sup>34</sup> In October 2009, Isaiah May was born in Rocky Mountain House, Alberta after a long and difficult forty-hour delivery.<sup>35</sup> At some point, his umbilical chord got wrapped around his neck several times, cutting off the oxygen supply to his brain.<sup>36</sup> Isaiah was airlifted to Stollery Children’s Hospital in Edmonton, where he was diagnosed with severe neonatal encephalopathy.<sup>37</sup> He was then dependent on mechanical ventilation.<sup>38</sup>

28. See generally Lee, *supra* note 8 (discussing medical futility disputes between providers and surrogates in the context of postoperative care).

29. *Id.*

30. See, e.g., RIGHT TO DIE, *supra* note 4, at § 13.01[B]. See also Thomas Wm. Mayo, *Living and Dying in a Post-Schiavo World*, 38 J. HEALTH L. 587, 602 n.68 (2005) (using the term “reverse right-to-die”).

31. See, e.g., Nancy Neveloff Dubler, *Conflict and Consensus at the End of Life*, HASTINGS CENTER REP., Nov.-Dec. 2005, at S19, S19; Leigh B. Middleditch, Jr. & Joel H. Trotter, *The Right to Live*, 5 ELDER L.J. 395, 395, 402, 404 (1997); Wesley J. Smith, *Suing for the Right to Live*, WEEKLYSTANDARD.COM, Mar. 10, 2004, <http://www.weeklystandard.com/Content/Public/Articles/000/000/003/836zeecs.asp>.

32. See, e.g., Smith, *supra* note 31.

33. See, e.g., Mary Ann Roser, *Existing ‘Medical Futility’ Law Works, Hospitals Say; Others at Hearing Disagree*, AUSTIN AM.-STATESMAN, Aug. 10, 2006, at B1.

34. Canadian Press, *Court Adjourns Case of Rocky Couple Fighting to Keep Infant on Life Support*, REDDEERADVOCATE.COM, Jan. 19, 2010, [http://www.albertalocalnews.com/redderadvocate/news/Court\\_adjourns\\_case\\_of\\_couple\\_fighting\\_to\\_keep\\_infant\\_on\\_life\\_support\\_82079392.html?mobile=true](http://www.albertalocalnews.com/redderadvocate/news/Court_adjourns_case_of_couple_fighting_to_keep_infant_on_life_support_82079392.html?mobile=true); Melissa Dominelli, *Parents to Battle AHS, Hospital to Keep their Infant Son on Life Support*, CTVEDMONTON.CA, Jan. 19, 2010, [http://edmonton.ctv.ca/servlet/an/local/CTVNews/20100118/edm\\_lifesupport\\_100118/20100118/](http://edmonton.ctv.ca/servlet/an/local/CTVNews/20100118/edm_lifesupport_100118/20100118/).

35. Dominelli, *supra* note 34.

36. Canadian Press, *supra* note 34.

37. Andrew Hanon, *Court Allows Baby Isaiah’s Life Support to Continue*, CALGARYSUN.COM, Jan. 28, 2010 [hereinafter *Life Support to Continue*], <http://www.calgarysun.com/news/alberta/2010/01/28/12641651.html>.

38. See Canadian Press, *supra* note 34; Dominelli, *supra* note 34; Andrew Hanon, *More Time to Line Up Specialists for Brain-Damaged Baby*, TORONTOSUN.COM, Jan. 28, 2010

On January 13, 2010, Alberta Health Services sent Isaiah's parents a letter explaining his prognosis and their planned course of action.<sup>39</sup> The physicians informed the parents that Isaiah would not recover from the severe lack of oxygen during his birth and that as a result, he suffered anoxic brain injury and irreversible brain damage.<sup>40</sup> They went on to tell Isaiah's parents that he would not recover from his injuries.<sup>41</sup>

Isaiah's doctors believed that all medical procedures had been exhausted. They wrote: "Your treating physicians regretfully have come to the conclusion that withdrawal of active treatment is medically reasonable, ethically responsible and appropriate. We must put the interests of your son foremost and it is in his best interests to discontinue mechanical ventilation support."<sup>42</sup> The letter went on to say: "Accordingly, it is with sadness that we are advising you that your treatment team will discontinue mechanical ventilation support to Isaiah after 2 p.m. Wednesday, January 20, 2010."<sup>43</sup>

Isaiah's parents disagreed with this prognosis and recommendation. They secured a temporary injunction against the removal of life support, so that they could obtain a second opinion.<sup>44</sup> Isaiah's parents argued that continued treatment was appropriate because Isaiah had already defied medical experts by living as long as he had and by growing and developing.<sup>45</sup> Isaiah's parents ultimately agreed to remove his ventilator after obtaining a second opinion, so subsequent court hearings were cancelled.<sup>46</sup>

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[hereinafter *Brain-Damaged Baby*], <http://www.torontosun.com/news/canada/2010/01/27/12636671.html>.

39. Canadian Press, *supra* note 34.

40. Dominelli, *supra* note 34.

41. *Id.*

42. Andrew Hanon, *Parents Get One-Week Reprieve for Baby on Life-Support*, CALGARYSUN.COM, Jan. 20, 2010 [hereinafter *Baby on Life Support*], <http://www.calgarysun.com/news/alberta/2010/01/19/12533411.html>.

43. Canadian Press, *supra* note 34.

44. EdmontonJournal.com, *Parents of Baby Isaiah Hope to Avoid Court Clash*, VANCOUVERSUN.COM, Feb. 20, 2010, <http://www.vancouversun.com/news/thewest/Baby+Isaiah+parents+await+results+assessment/2587211/story.html>; *Brain-Damaged Baby*, *supra* note 38; Lisa Priest, *Baby Isaiah to Remain on Life Support - for Now*, GLOBE & MAIL, Jan. 28, 2010, at A7.

45. *Brain-Damaged Baby*, *supra* note 38; CBCNews, *Parents Find Expert to Assess Baby on Life-Support*, CBCNEWS, Jan. 27, 2010, <http://www.cbc.ca/health/story/2010/01/27/edmonton-alberta-baby-isaiah-stays-on-ventilator.html#ixzz0e3ygOQLr> (quoting Isaiah's father as saying that, "[e]very time I hold him, he's non-stop moving, and he moves his head . . . He opens his eyes, his eyelids, a little bit and I mean, every little thing is an improvement, right?").

46. CBC News, *Baby Isaiah Dies in Edmonton Hospital*, CBCNEWS, Mar. 11, 2010, <http://www.cbc.ca/canada/edmonton/story/2010/03/11/edmonton-baby-isaiah-court-appearance-cancelled.html> (discussing the Mays' decision to take Isaiah off of the ventilator).

Obviously, baby Isaiah lacked the capacity to make healthcare decisions for himself.<sup>47</sup> But even in futility disputes involving *adult* patients, the patient almost always lacks capacity.<sup>48</sup> Either because of encephalopathy related to the disorder or because she is sedated, the patient is almost never able to communicate with providers at the time a decision must be made.<sup>49</sup> Therefore, these decisions are almost always made by surrogates.

Unfortunately, there is a significant rate of conflict between healthcare providers and surrogates. In most cases, the surrogate and the health care provider disagree over whether LSMT provides benefit because of a communication failure.<sup>50</sup> The surrogate and the provider perceive the situation differently.<sup>51</sup> In other cases, the disagreement is normative.<sup>52</sup> But, whether for factual or normative reasons, the provider and surrogate

47. "Capacity" is typically defined as an "individual's ability to understand the significant benefits, risks and alternatives to proposed health care and to make and communicate a health-care decision." DEL. CODE ANN. tit. 16, § 2501(d) (2003). See also ALA. CODE § 22-8A-11(a)(1)a. (LexisNexis 2006) (allowing a surrogate in consultation with the attending physician to make LSMT decisions if the patient "is no longer able to understand, appreciate, and direct his or her medical treatment").

48. See e.g., Alexandre Lautrette et al., *Surrogate Decision Makers for Incompetent ICU Patients: a European Perspective*, 14 CURRENT OPINION CRITICAL CARE 714, 716 (2008) (discussing the capacity of patients and the use of surrogates in the ICU).

49. *Id.* at 715. See MANAGING DEATH IN THE ICU: THE TRANSITION FROM CURE TO COMFORT 236 (J. Randall Curtis & Gordon D. Rubenfeld eds., 2001); Thomas J. Prendergast et al., *A National Survey of End-of-Life Care for Critically Ill Patients*, 158 AM. J. RESPIRATORY CARE MED. 1163, 1166 (1998); Susan M. Parks & Laraine Winter, *End-of-Life Decision Making for Cancer Patients*, 36 PRIMARY CARE CLINICAL OFFICE PRACTICE 811, 813 (2009) ("Most Americans are decisionally incapacitated at the time of death, usually because of dementia, delirium, coma, or PVS."); Maria J. Silveira et al., *Advance Directives and Outcomes of Surrogate Decision Making before Death*, 362 NEW ENG. J. MED. 1211, 1214 (2010); Elizabeth K. Vig et al., *Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision Making*, 54 J. AM. GERIATRICS SOC'Y 1688 (2006). But cf. *Burke v. Gen. Med. Council* [2005] EWCA Civ 1003, [2]-[5] (appeal taken from Eng.) (patient with capacity litigating a futility dispute concerning his own future treatment).

50. See Pope & Waldman, *supra* note 11, at 153 (suggesting that most surrogates eventually agree with the health care team's recommendation after the patient's condition and options are fully explained). See also ANTHONY BACK ET AL., *MASTERING COMMUNICATION WITH SERIOUSLY ILL PATIENTS: BALANCING HONESTY WITH EMPATHY AND HOPE* 1-6 (2009) (discussing the importance of physician communication skills in the context of seriously ill patients).

51. See David E. Weissman et al., *The Family Meeting: Causes of Conflict*, FAST FACTS AND CONCEPTS (2010), <http://www.mcw.edu/FileLibrary/User/jrehm/fastfactpdfs/Concept225.pdf>.

52. See JOSEPH J. FINS, *A PALLIATIVE ETHIC OF CARE: CLINICAL WISDOM AT LIFE'S END* 82, 84 (2006) (explaining how futility disputes result from clinicians and families "operating upon different assumptions" because of miscommunication concerning "basic information about diagnosis, prognosis, and remaining [treatment] options").

disagree because they have different goals.<sup>53</sup> "The patient's goals might include cure, amelioration of disability, palliation of symptoms, reversal of disease processes, or prolongation of life. The provider, on the other hand, might judge these goals to be impossible, virtually impossible, or otherwise inappropriate under the circumstances."<sup>54</sup>

There is, in short, a demonstrable gap between the goals of physicians and the goals of surrogates. In one recent study, seventy-two percent of the public thought that patients have a right to demand treatment that their physician's believe will not help.<sup>55</sup> Only forty-four percent of physicians agreed.<sup>56</sup> Similarly, twenty-one percent surrogates thought that even when doctors believe there is "no hope of recovery," all efforts should continue indefinitely.<sup>57</sup> Only 2.5% physicians agreed.<sup>58</sup>

### 1. Physician Reasons for Refusing Requested Treatment

Healthcare providers have several reasons for wanting to refuse surrogate-requested LSMT.<sup>59</sup> First, they want to prevent patient suffering since aggressive treatment can cause just that.<sup>60</sup> It is unacceptable if there is no countervailing benefit to be achieved by the treatment.<sup>61</sup> Continued interventions can be inhumane, invasive, pointless, intrusive, cruel, burdensome, abusive, degrading, obscene, violent, or grotesque.<sup>62</sup> CPR,

53. Cf. Thomas Wm. Mayo, *Health Care Law*, 53 SMU L. REV. 1101, 1110 n.78 (2000) (describing the dispute as being "what constitutes a 'benefit' to the patient").

54. Pope, *supra* note 19, at 10.

55. Lenworth M. Jacobs et al., *Trauma Death: Views of the Public and Trauma Professionals on Death and Dying from Injuries*, 143 ARCHIVES SURGERY 730, 732-33 (2008).

56. *Id.* at 733.

57. *Id.* at 732 tbl.3.

58. *Id.*

59. However, some providers actually provide as much as or even more treatment than surrogates desire.

60. See LAWRENCE J. SCHNEIDERMAN & NANCY S. JECKER, *WRONG MEDICINE: DOCTORS, PATIENTS, AND FUTILE TREATMENT* 101 (1995).

61. Plaintiffs' Verified Complaint at 8, *Gonzales v. Seton Family of Hospitals*, No. A07CA267 (W.D. Tex. Apr. 4, 2007) ("[T]he 'burden' of his treatment outweighs the benefit to E.G. [Emilio] or his mother.").

62. See, e.g., *In re Doe*, 418 S.E.2d 3, 4 (Ga. 1992) (Hospital alleged continued treatment would constitute "medical abuse."); *Wendland v. Sparks*, 574 N.W.2d 327, 328-29 (Iowa 1998) (Doctor unilaterally decided not to attempt CPR as "an act of mercy" because he could not "do it to her."); *In re Dinnerstein*, 380 N.E.2d 134, 137 (Mass. App. Ct. 1978) (characterizing LSMT as "pointless, even cruel, prolongation of the act of dying"); Brief for Appellants at 3, *In re Baby "K"*, 16 F.3d 590 (4th Cir. 1994) (No. 93-1899), 1993 WL 13123742 ("This tragic case involves a parent's attempt to require physicians to provide to a dying infant treatment that is medically unreasonable, invasive, burdensome, inhumane, and inappropriate."); John Altomare & Mark Bolde, *Nguyen v. Sacred Heart Medical Center*, 11 ISSUES L. & MED. 199, 200 (1995) (Hospital alleged continued treatment was "inhumane.");

for example, can be painful, causing rib or sternal fractures in over fifty percent of cases.<sup>63</sup> Health care providers want to relieve and shorten patient suffering, not cause or prolong it.<sup>64</sup>

Second, physicians want to protect patient autonomy. In many cases, the aggressive treatment demanded by a surrogate is treatment that the patient does not want.<sup>65</sup> And even when patient preferences are unknown, continued treatment is not always in the patient's best interests.<sup>66</sup> Furthermore, providing unwanted treatment not only violates the patient's bodily integrity, but also the patient's decisional autonomy by undermining the patient's wishes regarding the location of her death (e.g. at home) and utilizing estate resources to pay medical bills that the patient may have wanted to go to other uses (e.g. grandchildren's education).

Third, physicians want to prevent family distress. If they act as though a medically inappropriate option were "available," then that would create a psychological burden on surrogates to select that option.<sup>67</sup> Naturally,

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Martha Kessler, *Court Orders Hospital to Comply with Decisions Made Under Health Proxy*, 13 HEALTH L. REP. (BNA) 527, 527 (2004) (Massachusetts General Hospital successfully argued to a Boston court that CPR for Barbara Howe would be "severe, invasive and harmful."); Liz Kowalczyk, *Hospital, Family Spar over End-of-Life Care*, BOS. GLOBE, Mar. 11, 2005, at A1 ("[T]his inhumane travesty has gone far enough . . . This is the Massachusetts General Hospital, not Auschwitz." (quoting Dr. Edwin Cassem)).

63. SCHNEIDERMAN & JECKER, *supra* note 60, at 94 ("[A]ttempted cardiopulmonary resuscitation could involve forceful, even violent, efforts at compressing the chest cage to the point of fracturing ribs . . ."); Yoshiaki Hashimoto et al., *Forensic Aspects of Complications Resulting from Cardiopulmonary Resuscitation*, 9 LEGAL MED. 94, 97 (2007) ("[W]e observed rib fractures in 52% of the cases [and] [s]ternal fractures were recognized in 39%."). See generally Paul C. Sorum, *Limiting Cardiopulmonary Resuscitation*, 57 ALB. L. REV. 617, 617 (1994) ("The patient will usually receive the following interventions: manual compressions of the chest . . . one or more jolts of electricity to the chest . . . and intravenous medications and fluids.").

64. See Alexander Morgan Capron, *Abandoning a Waning Life*, HASTINGS CENTER REP., July-Aug. 1995, at 24, 24 (Unilateral termination can avoid "mistreating the patient."); SCHNEIDERMAN & JECKER, *supra* note 60, at 100-01 (The Hippocratic Oath supports physicians' refraining from providing futile care.). Cf. John C. Fletcher, *The Baby K Case: Ethical and Legal Considerations of Disputes About Futility*, 11 BIOLAW S:219, S:224 (describing a situation where the physicians initially provided LSMT with the hope that the surrogate would decide to have it removed).

65. *In re Livadas*, No. 08/037030 (N.Y. Apr. 28, 2008).

66. See generally *Bernstein v. Superior Court*, No. B212067, 2009 WL 224942 (Cal. Ct. App. Feb. 2, 2009).

67. See, e.g., George J. Annas, *Asking the Courts to Set the Standard of Emergency Care—The Case of Baby K*, 330 NEW ENG. J. MED. 1542, 1543 (1994) (calling the provision of mechanical ventilation to Baby K after birth a "medical misjudgment" that gave the mother a false impression); Allan S. Brett, *Futility Revisited: Reflections on the Perspectives of Families, Physicians, and Institutions*, 17 HEALTHCARE ETHICS COMMITTEE F. 276, 281, 282 (2005) (arguing that when a physician believes that additional treatment is inappropriate he should

families want to take at least all reasonable measures. Furthermore, it is unfair and deceptive to offer an option where there really is none.<sup>68</sup> Often the surrogate wants the burden of decision lifted from her.<sup>69</sup> And even if not the surrogate, other family members are often relieved to see the patient's preferences or best interests protected.<sup>70</sup>

Fourth, physicians want to preserve the integrity of the medical profession. Those in the health profession surely must have some role in defining the ends and goals of medicine because the medical profession is a self-governing one with its own standards of professional practice.<sup>71</sup> The "integrity of the medical profession" is an important societal interest that must be balanced against patient autonomy.<sup>72</sup> Many health care providers

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express that view and justify it to the family). *But cf.* Fletcher, *supra* note 64, at S:224 (suggesting that the court documents in *Baby K* showed the physicians had good reasons to intubate).

68. See Howard Brody, *The Physician's Role in Determining Futility*, 42 J. AM. GERIATRICS SOC'Y 875, 876-77 (1994) (suggesting that it is unethical to mislead patients by falsely raising hopes); Terese Hudson, *Are Futile-Care Policies the Answer?: Providers Struggle with Decisions for Patients Near the End of Life*, HOSPS. & HEALTH NETWORKS, Feb. 20, 1994, at 26, 26-28 (quoting John Popovich as saying that "physicians who offer futile, meaningless care are charlatans"); John J. Paris et al., *Has the Emphasis on Autonomy Gone Too Far? Insights from Dostoevsky on Parental Decisionmaking in the NICU*, 15 CAMBRIDGE Q. HEALTHCARE ETHICS 147, 150 (2006) (arguing that when faced with futile LSMT for an infant, a physician should explain to the parent(s) "that additional aggressive interventions or escalation of treatment will be unavailing" and then emphasize that comfort care will be continued in order to prevent giving parents "false hopes and unrealistic expectations"); Tom Tomlinson & Diane Czlonka, *Futility and Hospital Policy*, HASTINGS CENTER REP., May-June 1995, at 28, 28, 29-30 (Offering futile care is "a bogus choice" and "a deception," and instead providers should seek "acceptance" of plan rather than "consent.").

69. See Ursula K. Braun et al., *Reconceptualizing the Experience of Surrogate Decision Making: Reports vs. Genuine Decisions*, 7 ANNALS FAM. MED. 249, 253(2009) ("Requests to 'do everything' should therefore initially be understood as a request for help with managing the [surrogate] decision-making burden.").

70. See generally Fine, *supra* note 16, at 71-72.

71. See Eric Gampel, *Does Professional Autonomy Protect Medical Futility Judgments?*, 20 BIOETHICS 92, 97 (2006) ("[A]n HCP may refuse treatments which the medical profession gauges to be inappropriate, i.e. as being inconsistent with the basic goals and values of medicine. This would mean that each HCP 'inherits' a right of refusal from the right of the medical profession to be a self-governing body, one which defines its own standards of professional practice.").

72. See *Washington v. Glucksberg*, 521 U.S. 702, 731 (1997) ("The State also has an interest in protecting the integrity and ethics of the medical profession."); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 426 (Mass. 1977) ("Prevailing medical ethical practice does not . . . demand that all efforts toward life prolongation be made . . . . [T]he prevailing ethical practice seems to be to recognize that the dying are more often in need of comfort than treatment."); *In re Quinlan*, 355 A.2d 647, 663 (N.J. 1976) ("The claimed interests of the State in this case are essentially the preservation and sanctity of human life and defense of the right of the physician to administer medical treatment according to his

do not consider the practice of medicine to include measures aimed solely at maintaining corporeal existence and perpetuating biological function.<sup>73</sup> Under these circumstances, providers feel that it is just “wrong” to provide treatment.<sup>74</sup> It is “bad medicine,” medicine being used for the wrong ends.<sup>75</sup> Moreover, they find it gruesome, distressing, and demoralizing to provide treatment that harms patients.<sup>76</sup>

best judgment.”); Matthew S. Ferguson, *Ethical Postures of Futility and California’s Uniform Health Care Decisions Act*, 75 S. CAL. L. REV. 1217, 1239 (2002) (noting that the UHCDA attempts to protect the ethical integrity of the medical profession). The legal profession is similar in this respect. While generally the client is in charge, lawyers can withdraw if “the client insists upon taking action that the lawyer considers repugnant . . . .” AMERICAN BAR ASSOCIATION, MODEL RULES OF PROFESSIONAL CONDUCT R. 1.16(b)(4) (2008). Lawyers also have obligations under Rule 11—they cannot file frivolous lawsuits even if the client demands it. See Jerold S. Solovy & Laura A. Kaster, *Signing Pleadings, Motions, and Other Papers; Representations to the Court; Sanctions*, in 2 MOORE’S FEDERAL PRACTICE § 11.11[5] (3d ed. 2009).

73. COLL. OF PHYSICIANS & SURGEONS OF MANITOBA, STATEMENT NO. 1602: WITHHOLDING AND WITHDRAWING LIFE-SUSTAINING TREATMENT 15-S4 (2008), <http://www.cpsm.mb.ca/statements/1602.pdf> (listing guiding principles for withholding and withdrawing life-sustaining treatment).

74. See Benjamin Weiser, *The Case of Baby Rena: Who Decides When Care Is Futile? A Question of Letting Go: A Child’s Trauma Drives Doctors to Reexamine Ethical Role*, WASH. POST, July 14, 1991, at A1 (“It was medicine being used for the wrong ends, and not only was it being used for the wrong ends, but it had a bad effect. It was making the child suffer.”).

75. *Id.*

76. See ROBERT ZUSSMAN, INTENSIVE CARE: MEDICAL ETHICS AND THE MEDICAL PROFESSION 109 (1992) (noting that doctors are “inclined toward activism”); Robert A. Burt, *The Medical Futility Debate: Patient Choice, Physician Obligation, and End-of-Life Care*, 5 J. PALLIATIVE MED. 249, 252 (2002) (recognizing that providing treatment can be distressing for physicians); Stacey Burling, *Penn Hospital to Limit Its Care in Futile Cases: Severely Brain-Damaged Patients Won’t Get Certain Treatments, as a Rule*, PHILA. INQUIRER, Nov. 4, 2002, at A1 (describing a situation where providing treatment was gruesome); Jan Hoffman, *The Last Word on the Last Breath*, N.Y. TIMES, Oct. 10, 2006, at F1 (“[D]oing CPR [to PVS and end-stage patients], felt not only pointless, but like I was administering final blows to someone who had already had a hard enough life.” (quoting Dr. Daniel Sulmasy)); Hudson, *supra* note 68, at 26 (stating that physicians find some LSMT demoralizing); Liz Kowalczyk, *Mortal Differences Divide Hospital and Patient’s Family*, BOST. GLOBE, Sept. 28, 2003, at A1 (nurse refused to participate in continued aggressive treatment of Barbara Howe); Kowalczyk, *supra* note 62, at A26 (“Howe’s longtime doctors and nurses believe . . . that keeping her alive is tantamount to torture.”); Elisabeth Rosenthal, *Rules on Reviving the Dying Bring Undue Suffering, Doctors Contend*, N.Y. TIMES, Oct. 4, 1990, at A1 (“Doctors and nurses . . . describe anger and anguish at being forced by a patient or family to inflict pain on the dying, knowing that it is to no avail.”); Weiser, *supra* note 74 (Physicians and nurses viewed every day that Baby Rena spent in the ICU as a “day of torture” and “viewed themselves as the torturers.”); Gregory Scott Loeben, *Medical Futility and the Goals of Medicine* (1999) (unpublished Ph.D. dissertation, University of Arizona) (on file with Journal of Health Law and Policy, Saint Louis University) (“If such judgments are meant to benefit anyone, it makes more sense to say that it is the physician . . . uncomfortable with the role [he is] being asked to play . . . .”). Cf. TOM L.



Fifth, physicians want to reduce moral distress.<sup>77</sup> Numerous measures show high levels of moral distress among healthcare providers, especially nurses, in situations where they are obligated to provide inappropriate treatment.<sup>78</sup> This moral distress can drive people from the profession and thus reduce access.<sup>79</sup> It can also reduce staffing levels and make people operate less well, adversely impacting other patients' quality of care.<sup>80</sup>

Sixth, physicians want to responsibly steward scarce resources. This includes hard resources like intensive care unit ("ICU") beds.<sup>81</sup> In under-

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BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 38 (5th ed. 2001) (defending the physician's right of "conscientious objection" where the patient request is for something "medically unconscionable").

77. See generally Karen M. Gutierrez, *Critical Care Nurses' Perceptions of and Responses to Moral Distress*, 24 *DIMENSIONS CRITICAL CARE NURSING* 229, 229 (2005) (defining moral distress "as the feelings and experiences which result from a moral conflict where one knows the correct action to take but constraints lead to either inability to implement this action or an attempt to carry out moral action which fails to resolve the conflict"); Ann B. Hamric et al., *Moral Distress in Health Care Professionals: What Is It and What Can We Do About It?*, *PHAROS*, Winter, 2006, at 17, 18 (discussing physician moral distress); Connie M. Ulrich et al., *Moral Distress: A Growing Problem in the Health Professions?*, *HASTINGS CENTER REP.* Jan.-Feb. 2010, at 20, 21 (recognizing the negative effects of moral distress on healthcare providers).

78. See, e.g., Anita Catlin et al., *A Potential Neonatal Nurse Response to Care Orders that Cause Suffering at the End of Life? A Study of a Concept*, 27 *NEONATAL NETWORK* 101, 102 (2008) (collecting quotations and authority); Edouard Ferrand et al., *Discrepancies Between Perceptions by Physicians and Nursing Staff of Intensive Care Unit End-of-Life Decisions*, 167 *AM. J. RESPIRATORY & CRITICAL CARE MED.* 1310, 1313 (2003) (reporting the results of a study designed to evaluate the perceptions of physicians and nursing staff concerning ICU end-of-life decisions); Ann B. Hamric, *Moral Distress and Nurse-Physician Relationships*, 12 *VIRTUAL MENTOR* 6, 7-8 (2010) (discussing evidence that supports that both physicians and nurses experience moral distress); Lilia Susana Meltzer & Loucine Missak Huckabay, *Critical Care Nurses' Perceptions of Futile Care and Its Effect on Burnout*, 13 *AM. J. CRITICAL CARE* 202, 202 (2004).

79. See Ann B. Hamric & Leslie J. Blackhall, *Nurse-Physician Perspectives on the Care of Dying Patients in Intensive Care Units: Collaboration, Moral Distress, and Ethical Climate*, 35 *CRITICAL CARE MED.* 422, 426 (2007) ("Almost half (45%) of the RNs had left (17%) or considered leaving (28%) a position because of moral distress.").

80. See Ellen H. Elpern et al., *Moral Distress of Staff Nurses in a Medical Intensive Care Unit*, 14 *AM. J. CRITICAL CARE* 523, 529 (2005); Judith M. Wilkinson, *Moral Distress in Nursing Practice: Experience and Effect*, 23 *NURSING F.* 16, 23 (1987) ("One of the most common, but unsuccessful, coping behaviors was avoidance of patients or of job situations."); Meltzer & Huckabay, *supra* note 78, at 206 ("The frequency with which critical care nurses encountered moral distress situations involving futile care was directly and significantly related . . . to the experience of emotional exhaustion . . . [which] occurs when a person's appraisal of occupational stressors exceeds his or her coping capabilities . . .").

81. See George A. Skowronski, *Bed Rationing and Allocation in the Intensive Care Unit*, 7 *CURRENT OPINION CRITICAL CARE* 480, 482-83 (2001) (describing ICU beds as scarce resources).

bedded regions, an ICU bed used by a patient in a persistent vegetative state with multi-organ failure is the very same bed that could be used to achieve recovery for an accident victim.<sup>82</sup> Physicians are also concerned with stewarding soft resources (e.g. dollars).<sup>83</sup> The billions spent treating persistent vegetative state ("PVS") patients could be used to cover more people who now have no coverage. As costs rise, premiums rise, and access drops.<sup>84</sup>

## 2. Surrogate Reasons for Requesting Non-recommended Treatment

While most surrogates accede to provider recommendations to move to comfort care, significant subsets of surrogates are often inclined to request that "everything [be] done."<sup>85</sup> There are many reasons that surrogates insist on continuing treatment their health care providers consider medically inappropriate. First, surrogates might think that the healthcare providers' prognosis is wrong because of skepticism about their prognostic abilities.<sup>86</sup> Or the distrust might go deeper. Surrogates might distrust that they are receiving proper care either because of their race,<sup>87</sup> socioeconomic status,<sup>88</sup>

82. See generally Robert K. Oye & Paul E. Bellamy, *Patterns of Resource Consumption in Medical Intensive Care*, 99 CHEST 685, 685 (1991) (explaining study on ICU resources used on futile medical treatment).

83. See Daniel P. Sulmasy et al., *Physicians' Ethical Beliefs About Cost-Control Arrangements*, 160 ARCHIVES INTERNAL MED. 649, 649-651 (2000) (discussing the financial incentives for physicians to control costs). But see Lawrence J. Schneiderman et al., *Medical Futility: Response to Critiques*, 125 ANNALS INTERNAL MED. 669, 673 (1996) (arguing that medical futility should have nothing to do with saving money or rationing resources). There are other justice-based concerns. See Michael Niederman & Jeffrey Berger, *The Delivery of Futile Care Is Harmful to Other Patients*, 38 CRITICAL CARE MED. S518 (2010).

84. Ezekiel J. Emanuel, *The Cost-Coverage Trade-off: "It's Health Care Costs, Stupid"*, 299 JAMA 947, 947-48 (2008).

85. See, e.g., John Ellement, *Woman Suing MGH Tells Court of Distress*, BOS. GLOBE, Apr. 8, 1995, at 18. See also SCHNEIDERMAN & JECKER, *supra* note 60, at 22-24 (Parents demanded "vigorous measures" to keep their daughter alive.); Donalee Moulton, *Death, Denial and the Law*, 40 MED. POST, May 4, 2004, at 29 ("[T]here is a greater sense of entitlement among patients, who are more likely to challenge doctors and question medical decisions.").

86. Lucas S. Zier et al., *Doubt and Belief in Physicians' Ability to Prognosticate During Critical Illness: The Perspective of Surrogate Decision Makers*, 36 CRITICAL CARE MED. 2341, 2342, 2345 (2008) (Eighty-eight percent of study participants "expressed doubt in physicians' ability to prognosticate."). See also Pam Belluck, *Even as Doctors Say Enough, Families Fight to Prolong Life*, N.Y. TIMES, Mar. 27, 2005, at A1 (reporting that some "patients and families . . . are skeptical of doctors' interpretations or intentions").

87. See FINS, *supra* note 52, at 78-79 ("An especially difficult dynamic can arise when the family believes that the patient's dire condition was precipitated by a medical error or if they are suspicious that substandard care is being provided because the patient is from a traditionally marginalized population."); Lee, *supra* note 8, at 483 (recognizing concerns among African Americans regarding healthcare discrimination); Kathryn L. Moseley et al.,

or their provider's financial incentives.<sup>89</sup> A significant volume of scientific literature demonstrates that patients from racial and ethnic minorities more frequently and more adamantly demand LSMT.<sup>90</sup>

Second, even if not distrustful, surrogates might be in denial or under a "therapeutic illusion" that the patient could recover or that a new therapy will come along.<sup>91</sup> Easy access to medical information online makes

*Futility in Evolution*, 21 CLINICS GERIATRIC MED. 211, 212-13 (2005) (discussing contributing factors to minorities, publicly insured patients, and uninsured patients' suspicion of physician motives); Mary Ellen Wojtasiewicz, *Damage Compounded: Disparities, Distrust, and Disparate Impact in End-of-Life Conflict Resolution Policies*, AM. J. BIOETHICS, Sept.-Oct. 2006, at 8, 9 (discussing race-specific vulnerability in LSMT decisions).

88. Kevin Fiscella, *Socioeconomic Status Disparities in Healthcare Outcomes: Selection Bias or Biased Treatment?*, 42 MED. CARE 939, 939-40 (2004) (stating that the relationship between socioeconomic status and health care quality includes patients' "attitudes" and "beliefs").

89. See Pope & Waldman, *supra* note 11, at 164-65 (discussing patients' concerns regarding physician financial incentives).

90. See generally William Bayer et al., *Attitudes Toward Life-Sustaining Interventions Among Ambulatory Black and White Patients*, 16 ETHNICITY & DISEASE 914, 914, 917 (2006) (confirming previous studies that show Black patients are more likely to use life-sustaining treatment than White patients); Ursula K. Braun et al., *Decreasing Use of Percutaneous Endoscopic Gastrostomy Tube Feeding for Veterans with Dementia – Racial Differences Remain*, 53 J. AM. GERIATRICS SOC'Y 242, 242, 244-45 (2005) (finding that "African Americans are more likely to receive a PEG tube than Caucasians"); Marion Danis, *Improving End-of-Life Care in the Intensive Care Unit: What's to Be Learned from Outcomes Research?*, 6 NEW HORIZONS 110, 113 (1998) (finding that nonwhite patients receive more DNR orders); Michael N. Diringer et al., *Factors Associated with Withdrawal of Mechanical Ventilation in a Neurology/Neurosurgery Intensive Care Unit*, 29 CRITICAL CARE MED. 1792, 1796 (2001) (discussing studies which found that African American patients want more life-sustaining treatments and are less likely to withdraw such treatment); Joanne Mills Garrett et al., *Life-Sustaining Treatments During Terminal Illness: Who Wants What?*, 8 J. GEN. INTERNAL MED. 361, 364 (1993) ("Black patients were almost three times as likely as white patients . . . to want more [life-sustaining] treatment..."); Faith P. Hopp & Sonia A. Duffy, *Racial Variations in End-of-Life Care*, 48 J. AM. GERIATRICS SOC'Y 658, 661 (2000) (describing a study which found that "blacks were less likely than whites to engage in advance care planning and to limit care at the time of death"); Hilary Waldman, *End-of-Life Care, Viewed in Stark Black and White*, L.A. TIMES, Feb. 6, 2006, at F5 (reporting that many African Americans have reservations about end-of-life palliative care and are less likely than whites to sign living wills or DNR orders). But see Amber E. Barnato et al., *Racial Variation in End-of-Life Intensive Care Use: A Race or Hospital Effect?*, 41 HEALTH SERVICES RES. 2219, 2228 (2006) (arguing that differences were attributable to the use of hospitals with higher ICU use rather than to racial differences).

91. See Stacey A. Tovino & William J. Winslade, *A Primer on the Law and Ethics of Treatment, Research, and Public Policy in the Context of Severe Traumatic Brain Injury*, 14 ANNALS HEALTH L. 1, 2-3 n.5, 26, 26 n.153 (2005) (discussing "therapeutic illusion" where patients have "false hopes despite the lack of future benefit"); Middleditch, Jr. & Trotter, *supra* note 31, at 402-03 (discussing "Society's Increasing Denial of Death").

surrogates more confident in opposing providers' recommendations.<sup>92</sup> Even in the face of clear and dire medical facts, family members often hold out hope that the patient will beat the odds.<sup>93</sup> In one study, thirty-two percent of surrogates elected to continue treatment for patients with less than one percent survival estimate.<sup>94</sup> Even more shocking is that eighteen percent wanted to continue treatment even when there was zero chance of survival.<sup>95</sup>

Third, even when they truly appreciate that the odds are exceedingly slim, surrogates might believe that those odds are still worth pursuing. They might believe that God will perform a miracle.<sup>96</sup> Or they might otherwise be

92. Julie Sneider, *End-of-Life Decisions: Medical Ethics Experts See Shift in Care Disputes*, MILWAUKEE BUS. J., Apr. 22, 2005, at A29.

93. See Todd Ackerman, *Hospital Rules to Unplug Baby Girl/Leukemia Patient's Parents Scramble to Find New Care Facility*, HOUS. CHRON., Apr. 30, 2005, at B1, available at [http://www.chron.com/CDA/archives/archive.mpl?id=2005\\_3866472](http://www.chron.com/CDA/archives/archive.mpl?id=2005_3866472) (reporting that the mother of Knya Dismuke-Howard, a 6-month old with leukemia in her brain, multiple organ failure, and a life-threatening antibiotic-resistant infection believed her daughter could "beat the odds . . . She's a fighter."); Belluck, *supra* note 86, at A1 ("Extraordinary medical advances have stoked the hopes of families."); Clare Dyer, *Doctors Need Not Ventilate Baby to Prolong His Life*, 329 BRIT. MED. J. 995, 995 (2004) (reporting that the mother of a terminally ill infant rejected medical advice because her baby was "a fighter" and "had lived longer than doctors had predicted"); Bill Murphy, *Life-and-Death Matter Goes to Court*, HOUS. CHRON., Mar. 18, 2001, at 37A (reporting that relatives opposed to removing life support "don't share the conclusion that his condition is hopeless"). Cf. *In re Guardianship of Schiavo*, 851 So.2d 182, 186 (Fla. Dist. Ct. App. 2003) ("[W]e understand why a parent . . . would hold out hope . . . . If Mrs. Schiavo were our own daughter, we could not but hold to such a faith.").

94. Lucas S. Zier et al., *Surrogate Decision Makers' Responses to Physicians' Predictions of Medical Futility*, 136 CHEST 110, 114 (2009).

95. *Id.*

96. Jacobs et al., *supra* note 55, at 734 (finding that more than sixty percent of the public believe that a person in a PVS state can be saved by a miracle). See, e.g., *In re Baby K*, 832 F. Supp. 1022, 1026 (E.D. Va. 1993) ("The mother opposes the discontinuation . . . because she believes that all human life has value . . . that God will work a miracle . . . ."); Lee, *supra* note 8, at 483 (stating religious views that "[God] will pull [the patient] through"); Lois M. Collins & Linda Thomson, *Boy Focus of Life-Death Battle: Parents Hope for Miracle; Doctors Say He Is Dead*, DESERET MORNING NEWS, Oct. 14, 2004, available at <http://www.deseretnews.com/article/595098138/Boy-focus-of-life-death-battle.html> (The parents sought an injunction to stop physicians from disconnecting their son from life support even though he was declared dead because they believed he was "a small miracle away from recovering."); *Parents Fear Home Delay May Keep 'Miracle' Baby Charlotte in Hospital*, BIRMINGHAM POST [UK], Jan. 7, 2006, [http://findarticles.com/p/news-articles/birmingham-post-england-the/mi\\_7996/is\\_2006\\_Jan\\_7/parents-fear-home-delay-miracle/ai\\_n37700884/?tag=content;col1](http://findarticles.com/p/news-articles/birmingham-post-england-the/mi_7996/is_2006_Jan_7/parents-fear-home-delay-miracle/ai_n37700884/?tag=content;col1) (reporting that the parents of Charlotte Wyatt "are committed Christians" who believe that "miracles do happen").

compelled by religious or cultural traditions.<sup>97</sup> Disputes involving these so-motivated surrogates tend to be the most intractable.<sup>98</sup>

Fourth, surrogates may feel a sense of responsibility or guilt with respect to their relationship to the patient.<sup>99</sup> They might be too grief stricken to stop treatment.<sup>100</sup> Or they might—consistent with the “technological imperative” in American medicine<sup>101</sup>—simply have a sense that the patient is entitled to

97. See, e.g., *Rideout v. Hershey Med. Ctr.*, 30 Pa. D. & C.4th 57, 85 (C.P. Dauphin County 1995) (parents opposed to removing ventilator from daughter because of “religious belief that all human life . . . has value and should be protected”); James Bopp, Jr. & Richard E. Coleson, *Child Abuse by Whom?—Parental Rights and Judicial Competency Determinations: The Baby K and Baby Terry Cases*, 20 OHIO N.U. L. REV. 821, 841 (1994) (“I cannot make that decision to terminate life. God did not give me that power.” (quoting Brief of Appellant, *In re Achtabowski*, No. 93-1247-AV (Mich. Cir. Ct. Aug. 12, 1993) (No. 170251), at 39)); Bill Murphy, *Comatose Man Dies After Battle over Life Support: Family Cited Spiritual Beliefs*, HOUS. CHRON., Mar. 23, 2001, at 29A, available at [http://www.chron.com/CDA/archives/archive.mpl?id=2001\\_3290826](http://www.chron.com/CDA/archives/archive.mpl?id=2001_3290826) (reporting that family was “spiritually and culturally opposed to removing life support”); John Carvel, *Muslim Family Lose Right-to-Life Appeal*, GUARDIAN, Sept. 2, 2005, <http://www.guardian.co.uk/society/2005/sep/02/health.uknews> (noting the “family’s religious conviction”); Lee, *supra* note 8, at 483 (suggesting that some surrogates respond that “nobody should be making decisions for God”); Emily Ramshaw, *Children Try to Keep Their Mother Alive*, DALLAS MORNING NEWS, Aug. 18, 2006, at 1B (“Ruthie Webster[] is deeply religious and believes only God should give and take life.”); Benjamin Weiser, *supra* note 74 (discussing the religious views of Baby Rena’s father).

98. Zier et al., *supra* note 94, at 115.

99. Hoffman, *supra* note 76, at F1 (“Families often believe that consenting to a DNR order implies they are giving up on their loved one, signing a death warrant.”); Lee, *supra* note 8, at 483 (citing a possible response to a physician’s call for an end to futile care as, “I’m not sure I can live with myself for the rest of my life if I let you pull the tube on him”); Paris et al., *supra* note 68, at 147-48; Arthur U. Rivin, *Futile Care Policy: Lessons Learned from Three Years’ Experience in a Community Hospital*, 166 W. J. MED. 389, 392 tbl.1 (1997) (identifying “[s]ense of heavy responsibility or guilt” as reason why family surrogates want continued futile care); Ann Wlazelek, *Pendulum Swings in Life-Saving Efforts: Hospitals’ Policies on Doing All They Can to Keep Patients Alive Have Changed*, MORNING CALL, June 13, 2004, [http://www.mcall.com/news/local/all-a1\\_5futilejun13,0,3836785.story](http://www.mcall.com/news/local/all-a1_5futilejun13,0,3836785.story) (“It’s dangerous to give the family the last word since guilt and a desire to do everything for mom or pop makes it emotionally impossible to stop any treatment.” (quoting Arthur Caplan)).

100. Rivin, *supra* note 99, at 392 tbl.1. See, e.g., Capron, *supra* note 64, at 24-25 (reporting that Massachusetts General wrote a unilateral DNR because “the family’s unpreparedness for their mother’s death did ‘not justify mistreating the patient’”); Ezekiel J. Emanuel & Linda L. Emanuel, *Proxy Decision Making for Incompetent Patients: An Ethical and Empirical Analysis*, 267 JAMA 2067, 2068-69 (1992) (discussing how surrogates face psychological stress when deciding to terminate life-sustaining treatments for loved ones).

101. The mindset is that because we can use a given technology, we *should* use that technology. See generally VICTOR R. FUCHS, WHO SHALL LIVE? HEALTH, ECONOMICS, AND SOCIAL CHOICE 94-95 (1974) (discussing how the “technological imperative” might be a contributing factor to rising health care costs); Kathy L. Cerminara, *Dealing with Dying: How Insurers Can Help Patients Seeking Last-Chance Therapies (Even When the Answer Is “No”)*, 15 HEALTH MATRIX 285, 296 (2005) (commenting on the technological imperative in American

everything.<sup>102</sup> Whatever the reason, more and more surrogates want their health care providers to “do everything.”<sup>103</sup>

### B. Prevalence of Futility Disputes

A leading health law treatise predicts that medical futility disputes are “likely to occupy as much, if not more [time and] judicial effort in the coming years as conventional end-of-life cases have in the last three decades.”<sup>104</sup> And the numbers are beginning to bear this out.<sup>105</sup> Nearly

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medicine); Robert L. Fine, *The History of Institutional Ethics at Baylor University Medical Center*, 17 BAYLOR U. MED. CTR. PROC. 73, 73-74 (2004) (stating the position taken by those who believe in the technological imperative).

102. See, e.g., Arthur E. Kopelman, *Understanding, Avoiding, and Resolving End-of-Life Conflicts in the NICU*, 73 MOUNT SINAI J. MED. 580, 582, 584 (2006) (discussing the patient perspective that every life has “great value and should be saved”); Alan Meisel, *The Role of Litigation in End of Life Care: A Reappraisal*, HASTINGS CENTER REP., Nov.-Dec. 2005, at S47, S49 (“A vocal proportion of the population . . . believes that life per se is a pearl beyond price and must be preserved at all costs . . . This set of beliefs [is] known as ‘vitalism’ . . .”); Rivin, *supra* note 99, at 392 tbl.2 (explaining that some doctors view themselves as “clinical warriors” fighting death); James J. Walter, *Medical Futility—An Ethical Issue for Clinicians and Patients*, PRACTICAL BIOETHICS, Summer 2005, at 1, 1 (“The distraught family is at the bedside, demanding that ‘everything be done’ to save their mother’s life.”). Particularly where LSMT is covered by insurance, it is easy for surrogates to insist on continued treatment. All the costs (economic, emotional, etc.) are externalities. The insurer (through other policyholders) pays. Health care providers, particularly nurses, bear the emotional burden of treating the patient. Cf. Robert M. Taylor & John D. Lantos, *The Politics of Medical Futility*, 11 ISSUES L. & MED. 3, 9 (1995) (discussing the burden to medical professionals and “to the other members of the insurance pool”). See also Todd Ackerman, *St. Luke’s Postpones Removal of Life Support*, HOUS. CHRON., Mar. 12, 2005, at B1 (“[T]he family understands there is no hope . . . [but] the decision when life support is removed should be ours, not a corporation’s.”).

103. See News Release, Pew Res. Ctr. People & Press, *More Americans Discussing—and Planning—End-of-Life Treatment: Strong Public Support for Right to Die* (January 5, 2006) (reporting that between 1990 and 2005, the percent of Americans who wanted a doctor to “do everything” increased from fifteen percent to twenty-two percent). See also Sneider, *supra* note 92 (“[M]ore families are challenging doctors who believe additional medical treatment of a critically ill patient is unwarranted.”).

104. RIGHT TO DIE, *supra* note 4, at § 13.01[D].

105. See, e.g., Belluck, *supra* note 86, at A1 (“The most common case that comes before the ethics committees . . . are families now insisting on treatment that the doctors believe is unwarranted.” (quoting Dr. John J. Paris)); Ron Hamel, *A Critical Juncture: Surveys of Ethicists and Mission Leaders Indicate Concerns About the Future of Ethics in the Catholic Health Ministry*, HEALTH PROGRESS, Mar.-Apr. 2009, at 12, 17 (“The most frequently mentioned issues . . . were end-of-life care and futile treatment.”); John M. Luce & Douglas B. White, *The Pressure to Withhold or Withdraw Life-Sustaining Therapy from Critically Ill Patients in the United States*, 175 AM. J. RESPIRATORY & CRITICAL CARE MED. 1104, 1107 (2007) (“[D]isagreements between families and clinicians on end-of-life care are commonplace in the United States.”); Renie Schapiro, *Power of Attorney Won’t Solve All Issues at End of Life*, MILWAUKEE J.-SENTINEL, May 19, 2008, at 2G (“This scenario is a composite of cases . . . that

one-third of ICU patients had conflicts associated with their care.<sup>106</sup> One recent study identified 974 futility disputes in sixteen hospitals over an average four-year period.<sup>107</sup>

Futility disputes are regularly identified as the single biggest ethical dilemma facing North American hospitals.<sup>108</sup> They now constitute the number one ethical challenge among the public in health care.<sup>109</sup> The debate over who decides when continued LSMT is inappropriate is "one of the most important and contentious in medical ethics."<sup>110</sup> It has become a "pressing issue of our times, whether we like it or not!"<sup>111</sup>

### C. Most Futility Disputes Are Resolved Collaboratively

While Alberta's Isaiah May case ended up in court, most futility disputes are resolved internally and informally by the health care team. Allowing surrogates "enough time is critically important to help them understand the situation and to let them assimilate with what is happening."<sup>112</sup> After the team discusses the patient's goals for treatment, the nature of the patient's condition, and the range of options, most surrogates eventually come to agree with the team's recommendation.

For example, in a multi-center study by Prendergast and colleagues, fifty-seven percent of surrogates agreed immediately with a provider-recommended care-plan, and ninety percent moved toward agreement within five days.<sup>113</sup> In a more recent study, Garros and colleagues found that consensus was reached in fifty-one percent of cases at the first meeting, in sixty-nine percent of cases after a second meeting, and ninety-seven

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regularly occur in hospitals and other health care facilities."); Keith M. Swetz et al., *Report of 255 Clinical Ethics Consultations and Review of the Literature*, 82 MAYO CLINIC PROC. 686, 688 (2007) (finding that futility disputes are one of the primary reasons for hospital ethics consultations).

106. Nathalie Danjoux Meth et al., *Conflicts in the ICU: Perspectives of Administrators and Clinicians*, 35 INTENSIVE CARE MED. 2068, 2069 (2009).

107. Emily Ramshaw, *Bills Challenge Limits for Terminal Patients: Some Say 10 Days to Transfer Isn't Enough Before Treatment Ends*, DALLAS MORNING NEWS, Feb. 15, 2007, at 1A.

108. See Reuters, *Death and Dying: When Is It Time to Let Go?*, CNN.COM, July 31, 2007, <http://www.cnn.com/2007/LIVING/wayoflife/07/27/livingwell.endoflife.reut/index.html>.

109. Jonathan M. Breslin et al., *Top 10 Health Care Ethics Challenges Facing the Public: Views of Toronto Bioethicists*, 6 BMC MED. ETHICS tbl.1 (2005).

110. Steven H. Miles, *Medical Futility*, 20 L. MED. & HEALTH CARE 310, 310 (1992).

111. AYUL M. ZAMIR, INTERN BETH 157 (2006).

112. A. A. Eduard Verhagen et al., *Conflicts About End-of-Life Decisions in NICUs in the Netherlands*, 124 PEDIATRICS e112, e117 (2009).

113. Thomas J. Prendergast, *Resolving Conflicts Surrounding End-of-Life Care*, 5 NEW HORIZONS 62, 67 (1997).

percent of cases after a third meeting.<sup>114</sup> In an even broader study of nearly 3,000 disputes, consensus was reached in all but sixty-five.<sup>115</sup>

In short, futility disputes are “usually resolved collaboratively by the treatment team and the family.”<sup>116</sup> Even when not settled there, “multi-disciplinary ethics consultation helps families accept treatment limitation” in nearly ninety percent of cases.<sup>117</sup> The focus of this article is on the remaining intractable disputes: “How to proceed when impasse persists remains an unsettled controversy.”<sup>118</sup> But first, we must more closely examine a key party to such disputes, the patient’s surrogate decision maker.

## II. THE ROLE OF SURROGATES

Patient autonomy is valued so highly in the United States that the patient does not lose the right of self-determination when she loses the capacity to make healthcare decisions for herself. Our individualistic consensus places “such a strong emphasis on the value of the patient” that medical decisions should “continue to be guided by that voice as much as possible, even when the patient has lost decision-making capacity.”<sup>119</sup>

A key method by which the patient can preserve her autonomy is by designating another person to direct the course of her medical treatment upon her incapacity.<sup>120</sup> For the sake of clarity and economy, I refer to this substitute decision maker as a “surrogate.”<sup>121</sup> In fact, there are three different types of surrogates. In this Section, I first describe these three basic types. I then explain the decision-making standards and criteria that these surrogates must employ when making healthcare decisions on behalf of incapacitated patients.

114. See Daniel Garros et al., *Circumstances Surrounding End of Life in a Pediatric Intensive Care Unit*, 112 PEDIATRICS e371, e373 (2003).

115. Robert L. Fine, *Point: The Texas Advance Directives Act Effectively and Ethically Resolves Disputes About Medical Futility*, 136 CHEST 963, 963, 967 (2009) (“[B]asic clinical ethics consultation alone . . . brought closure to . . . 86% of explicit futility cases.”).

116. Robert L. Fine, *Correspondence, Tackling Medical Futility in Texas*, 357 NEW ENG. J. MED. 1558, 1558 (2007) (responding to an article of the same name authored by Prof. Truog).

117. Fine, *supra* note 115, at 1558.

118. Mark D. Siegel, *End-of-Life Decision Making in the ICU*, 30 CLINICS CHEST MED. 181, 189 (2009).

119. Bruce Jennings, *Ethical Dilemmas in Surrogate Decision Making*, in LIVING WITH GRIEF: ETHICAL DILEMMAS AT THE END OF LIFE 157, 158 (Kenneth J. Doka et al. eds., 2005).

120. See generally William M. Lamers, Jr., *Autonomy, Consent, and Advance Directives*, in LIVING WITH GRIEF: ETHICAL DILEMMAS AT THE END OF LIFE 106, 109-10, 117 (Kenneth J. Doka et al. eds., 2005) (explaining the concept of autonomy and the use of advance directives).

121. See RIGHT TO DIE, *supra* note 4, at § 3.02[B].



### A. *Types of Surrogates*

There are three basic types of surrogates, corresponding to the three basic ways through which surrogates get their decision-making authority.<sup>122</sup> First, the patient herself can designate her surrogate in an advance directive. This type of agent is normally referred to as an “agent” or “attorney-in-fact.”<sup>123</sup> Second, the court can appoint a surrogate. This type of surrogate is normally referred to as a “guardian” or “conservator.”<sup>124</sup> Third, if neither of these is available, the healthcare provider can designate a surrogate pursuant to rules for default decision makers. This type of surrogate is normally referred to as a “surrogate” or “proxy.”<sup>125</sup>

#### 1. Patient-Designated Surrogates: Agents and Attorneys-in-Fact

Every state legislature has established a decision-making process that allows competent patients to appoint an agent to decide about healthcare in the event that they become unable to decide for themselves.<sup>126</sup> This appointment can be made through a simple form typically referred to as an advance directive or durable power of attorney for healthcare.<sup>127</sup> Furthermore, even if a patient has not undertaken the execution formalities to appoint an agent, they can often designate a surrogate, even orally.<sup>128</sup> Such a designation is made directly by the patient to healthcare providers, letting them know whom the patient wants to speak on her behalf.<sup>129</sup>

122. See generally *id.* at §§ 8.01-8.11 (outlining the jurisprudence of selecting surrogate decision makers).

123. *Id.* at § 7.01[B][5].

124. *Id.* at §§ 3.04[C], 7.01[B][6].

125. *Id.*, at § 7.01[B][6]. Sometimes no surrogate is reasonably available. Such a case is not really a futility dispute because not only does no one challenge the provider, but also the provider is the authorized decision-maker in many jurisdictions. See, e.g., TENN. CODE ANN. § 68-11-1806(c)(5) (2006) (providing the authority for a physician to become the decision-maker for a patient if no eligible surrogate is available). Cf. Sumeeta Varma & David Wendler, *Medical Decision Making for Patients Without Surrogates*, 167 ARCHIVES INTERNAL MED. 1711, 1711-12 (2007) (discussing the challenges presented by patients without surrogates); Douglas B. White et al., *Life Support for Patients Without a Surrogate Decision Maker: Who Decides?*, 147 ANNALS INTERNAL MED. 34, 37-38 (2007) (documenting the difficulty and frequency of life support decisions made for patients without surrogates). See also BLACK'S LAW DICTIONARY 1346 (9th ed. 2009) (defining “proxy”).

126. See generally RIGHT TO DIE, *supra* note 4, at §§ 7.01[A], 7.13 tbl. 7-1.

127. *Id.* at §§ 7.01 [A]-[B].

128. *Id.* at § 7.03[B][2]. See, e.g., TENN. CODE ANN. § 68-11-1806(a) (2006).

129. See, e.g., ALASKA STAT. § 13.52.030 (2008); CAL. PROB. CODE §§ 4711, 4714 (West 2009); DEL. CODE ANN. Health & Safety 16, § 2507 (2003); HAW. REV. STAT. ANN. § 327E-5 (LexisNexis 2008); MISS. CODE ANN. § 41-41-205 (2005). See generally CHARLES P. SABATINO, U.S. DEP'T HEALTH & HUMAN SERVS., ADVANCE DIRECTIVES AND ADVANCE CARE

Upon a determination that the patient has lost capacity, the agent typically has the right to make all healthcare decisions that the patient could have made for herself, unless the patient has explicitly limited the agent's authority.<sup>130</sup> And providers must comply with the healthcare decisions made in good faith by an agent to the same extent that they must comply with decisions made by the patient herself.<sup>131</sup>

## 2. Physician-Designated Surrogates: Default Surrogates and Proxies

If the patient has neither appointed an agent nor designated a surrogate, or if none is reasonably available at the time a decision must be made, then the healthcare provider can designate a surrogate.<sup>132</sup> The provider makes the designation on the patient's behalf pursuant to default surrogate statutes in almost every state.<sup>133</sup> These statutes specify a priority list of individuals whom the physician should or must designate.<sup>134</sup> Typically, at the top of this hierarchy are the patient's spouse, adult child, parent, and adult sibling.<sup>135</sup> These relatives are likely not only to know the convictions and beliefs of the patient but also to be concerned for the

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PLANNING: LEGAL AND POLICY ISSUES 22 (2007), <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.pdf> (discussing oral instructional directives and oral designation of surrogates).

130. See RIGHT TO DIE, *supra* note 4, at § 7.01[B][4].

131. AM. MED. ASS'N, COUNCIL ON ETHICAL AND JUDICIAL AFF., CODE OF MEDICAL ETHICS OF THE AMERICAN MEDICAL ASSOCIATION 252 (2008) [hereinafter AMA CODE OF ETHICS] ("Physicians should recognize the proxy or surrogate as an extension of the patient, entitled to the same respect as the competent patient.").

132. This type of surrogate is sometimes referred to as a "proxy." See, e.g., FLA. STAT. ANN. § 765.401 (West 2005).

133. New York (until June 2010) and Missouri currently lack effective mechanisms for physician-designation of surrogates. Thaddeus Mason Pope, *Legal Briefing: Advance Care Planning*, 20 J. CLINICAL ETHICS 362, 362-63 (2009); Susan E. Hickman et al., *The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation*, 36 J.L. MED. & ETHICS 119, 126 (2008).

134. Sometimes the list is not prioritized, in which case the surrogate can be selected from anyone anywhere on the list. See, e.g., COLO. REV. STAT. §§ 15-18.5-101-103 (2009); MICH. COMP. LAWS ANN. §§ 333.5653-5661 (West 2009); TENN. CODE ANN. §§ 68-11-1806(c) (2008); N.D. CENT. CODE § 23-12-13 (2002).

135. Hickman et al., *supra* note 133, at 122. Sometimes the surrogates of a certain class are evenly divided, such that a court-appointed guardian may need to make the decision. This happened in the case of Jason Childress, whose parents could not agree whether to consent to the University of Virginia's removal of life support. See Va. Law. WKLY., *A Family Divided Leaves Life-or-Death Decision to Man's Guardian*, VA. LAW. WKLY., Sept. 8, 2003, available at <http://valawyersweekly.com/blog/2003/09/08/a-family-divided-leaves-life-or-death-decision-to-mans-guardian/>. Such situations are outside the scope of this article.

patient. Since most patients do not engage in adequate advance care planning, default surrogates are the most numerous type of surrogate.<sup>136</sup>

### 3. Court-Designated Surrogates: Guardians and Conservators

The final way in which a person can become a substitute decision maker for a patient is to get appointed by a court. For patients without capacity, it is sometimes necessary to petition a court to appoint a guardian or conservator. The petition is usually filed by a relative or by the administrator of a long-term care facility where the patient resides.<sup>137</sup> After the appointment, the court supervises the guardian's choices on behalf of the patient, to ensure that the patient is getting appropriate medical care.<sup>138</sup> Because this process can be cumbersome and expensive, comparatively few surrogates are guardians.<sup>139</sup>

#### B. Duties of Surrogates

Whether patient-, physician-, or court-designated, a surrogate is an "extension of the patient."<sup>140</sup> The surrogate stands in the shoes of the patient. Accordingly, "the surrogate must make the medical choice that the patient, if competent, would have made and not one that the surrogate might make for himself or herself . . . ."<sup>141</sup> The surrogate is "obligated to suppress his or her own judgment in favor of 'channeling' what the [patient] would have done."<sup>142</sup> A well-respected how-to guide for surrogates advises

136. Alan Meisel & Bruce Jennings, *Ethics, End-of-Life Care, and the Law: Overview*, in *LIVING WITH GRIEF: ETHICAL DILEMMAS AT THE END OF LIFE* 72 (Kenneth J. Doka et al. eds., 2005).

137. Kris Bulcroft et al., *Elderly Wards and Their Legal Guardians: Analysis of County Probate Records in Ohio and Washington*, 31 *GERONTOLOGIST* 156, 157 (1991). See generally PETER J. BUTTARO, *LEGAL GUIDE FOR LONG-TERM CARE ADMINISTRATORS* (Emily L.H. Buttaro ed., 1999).

138. See Naomi Karp & Erica F. Wood, *Guardianship Monitoring: A National Survey of Court Practices*, 37 *STETSON L. REV.* 143, 146 (2007) (noting that "court monitoring of guardians is required to ensure the welfare of incapacitated persons . . .").

139. See Meisel & Jennings, *supra* note 136, at 72.

140. AMA CODE OF ETHICS, *supra* note 131, at 252.

141. *In re Guardianship of Browning*, 568 So. 2d 4, 13 (Fla. 1990). See also Lawrence A. Frolik, *Is a Guardian the Alter Ego of the Ward?*, 37 *STETSON L. REV.* 53, 63 ("[T]he law favors . . . doing what the ward would have done."); *id.* at 65 ("[I]f the guardian is expected to act as the ward would have acted but for the incapacity, then the guardian is essentially the agent of the ward . . . ."); *id.* at 67 ("[T]he substituted-judgment doctrine is the overwhelming choice . . . .").

142. Frolik, *supra* note 141, at 65. See also RESTATEMENT (THIRD) OF AGENCY § 8.01 cmt. b (2005) ("[T]he general fiduciary principle requires that the agent subordinate the agent's interests to those of the principal and place the principal's interests first . . . ."); *In re Martin*,

them “to decide as the patient would, even if the decision goes against the way you would decide for yourself.”<sup>143</sup>

The standards for surrogate decision-making are basically the same for all three types of surrogates.<sup>144</sup> These standards are usually specified in state statutes, and there is substantial uniformity across the country.<sup>145</sup> There is generally a three-step hierarchy.<sup>146</sup> “Surrogates should apply these standards sequentially in the order given: [1] expressed wishes, [2] substituted judgment, and then [3] best interest.”<sup>147</sup>

### 1. Subjective Standard: Implement the Patient’s Instructions

Sometimes, before losing capacity, the patient might have spoken directly to the issue of life-sustaining treatment, expressing a very clear preference for or against it in certain circumstances. Such instructions are normally memorialized in an advance directive or a living will.<sup>148</sup> In such cases, the advance directive becomes a “self-initiating consent

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538 N.W.2d 399, 408 (Mich. 1995) (“[T]he right the surrogate is seeking to effectuate is the incompetent patient’s right to control his own life . . .”).

143. AM. BAR. ASS’N COMM’N ON LAW & AGING, MAKING MEDICAL DECISIONS FOR SOMEONE ELSE: A HOW-TO GUIDE 4 (2009), available at <http://www.abanet.org/aging/pdfs/genlproxyguide2009.pdf> (emphasis added). See also Jennings, *supra* note 119, at 163 (“The surrogate is expressly forbidden to make the decision based on what the surrogate would want done. Surrogates must not project their own hopes, fears, emotions, expectations or beliefs onto the patient.”).

144. See Frolik, *supra* note 141, at 85 (“[T]here is no defensible reason to apply different requirements to proxies whose authority arises from judicial appointment, statutory designation, or having been named by the principal.”); CLAIRE C. OBADE, PATIENT CARE DECISION-MAKING: A LEGAL GUIDE FOR PROVIDERS §11:9 (Thomson/West 2008) (explaining various methods for surrogate decision-making).

145. See, e.g., WIS. STAT. § 155.20(5) (2007-08) (“The health care agent shall act in good faith consistently with the desires of the principal . . . In the absence of a specific directive by the principal or if the principal’s desires are unknown, the health care agent shall, in good faith, act in the best interests of the principal in exercising his or her authority.”).

146. RIGHT TO DIE, *supra* note 4, at § 4.01[B].

147. James L. Bernat, *Ethical Issues in the Treatment of Severe Brain Injury: The Impact of New Technologies*, ANNALS N.Y. ACAD. SCI., Mar. 2009, at 117, 123. Admittedly, the *de facto* standard is agreement. See RIGHT TO DIE, *supra* note 4, at § 4.01. There may indeed be a chasm between the statutorily specified standards and those that are applied at the bedside. See, e.g., Berger et al., *Surrogate Decision Making: Reconciling Ethical Theory and Clinical Practice*, 149 ANNALS INTERNAL MED. 48, 48 (2008). But it is outside the scope of this article to evaluate or analyze the merits of the decision-making standards. The mission of this article is to examine how and to what extent those standards can be used to resolve utility disputes.

148. Usually these are written and witnessed documents that follow the IF . . . THEN . . . format, where the “IF” refers to a hypothetical mental or physical condition and the “THEN” indicates the person’s wishes regarding treatment and care. See Meisel & Jennings, *supra* note 136, at 76.

document.<sup>149</sup> Where such formal documentation is available, the surrogate's role is no longer that of "decision maker," so much as that of "reporter" or "enforcer" of the patient's preferences.<sup>150</sup> The surrogate is charged merely with implementing what the patient has already "actually decided."<sup>151</sup>

In such situations, the surrogate's discretion is normally constrained by the patient's written instructions.<sup>152</sup> Massachusetts law, for example, provides: "An agent shall have the authority to make any and all health care decisions on the principal's behalf that the principal could make, including decisions about life-sustaining treatment, *subject, however, to any express limitations in the health care proxy.*"<sup>153</sup> The agent, after all, is only a second-best means to protecting patient autonomy. Almost always preferable is subjective first-hand evidence, evidence of the patient's very own decisions about her healthcare treatment.<sup>154</sup>

## 2. Substituted Judgment: Implement the Patient's Preferences

While theoretically the most straightforward standard, the circumstances rarely provide for application of the subjective standard. First, few patients have left specific treatment instructions.<sup>155</sup> Second, even when patients have

149. Casey Frank, *Surrogate Decision-Making for "Friendless" Patients*, COLO. LAW., Apr. 2005, at 71, 71.

150. Braun et al., *supra* note 69, at 250.

151. See generally RIGHT TO DIE, *supra* note 4, at § 4.05 [A] (noting that under the subjective standard, the surrogate makes any decisions regarding forgoing life-sustaining treatment "based on instructions the patient *actually* gave before losing decisionmaking" ability); ALA. CODE § 22-8A-6 (2006) ("An individual designated to make decisions regarding the providing, withholding, or withdrawing of life-sustaining treatment . . . for another . . . shall make those decisions according to the specific instructions or directions given to him or her in the designation or other document or by the individual making the designation.").

152. This is true unless the patient specifically granted otherwise. See *infra* notes 432 to 433 and accompanying text. See also RIGHT TO DIE, *supra* note 4, at § 4.05 [B] (noting that the subjective standard gives no credence to speculation on the surrogate's behalf, but rather requires actual knowledge of the patient's wishes).

153. MASS. ANN. LAWS ch. 201D § 5 (LexisNexis 2009) (emphasis added).

154. See, e.g., *In re Estate of Longeway*, 549 N.E.2d 292, 299 (Ill. 1989) ("[T]he surrogate first tries to determine if the patient had expressed explicit intent regarding this type of medical treatment . . .").

155. SABATINO, *supra* note 129, at 10-11. See News Release, Am. Bar Ass'n, ABA-Commissioned Poll Finds More than Twice as Many Americans Talk About Planning For Healthcare Emergencies than Take Action (May 14, 2008), available at [http://www.abanet.org/abanet/media/release/news\\_release.cfm?releaseid=345](http://www.abanet.org/abanet/media/release/news_release.cfm?releaseid=345) (stating that less than thirty percent of Americans have advance directives); *Honoring Final Wishes: How to Respect [Americans'] Choices at the End of Life: Hearing Before the S. Comm. on Aging*, 110th Cong. 3 (2008) (statement of Sen. Sheldon Whitehouse) ("Even among terminally ill patients fewer than 50 percent have an 'advanced directive' in their medical record.").

memorialized written instructions, they are often unavailable at the time a decision must be made.<sup>156</sup> Third, even when instructions are available, they often fail to address the situation at hand.<sup>157</sup>

Consequently, surrogates usually must instead apply the substituted judgment standard. Without express, specific instructions to guide them, surrogates must engage in some speculation and “infer” the patient’s wishes from her prior statements and conduct.<sup>158</sup> In short, “[w]hen there is evidence of the patient’s preferences and values, [then] decisions concerning the patient’s care should be made by substituted judgment.”<sup>159</sup> In describing the substituted judgment standard, the *AMA Code of Medical Ethics* states:

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156. Not only has a minority of the population completed advance directives, but also most advance directives in that subset are ineffective because either their existence or location is unknown. See statement of Sen. Whitehouse, *supra* note 155 (“[R]oughly 70 percent of physicians whose patients have advance directives do not know about them.”).

157. As discussed below, this is demanding because it requires that the instructions (1) be directed at the treatment in question, (2) be clear and unequivocal, (3) concern the patient’s own situation, (4) be solemn circumstances. *RIGHT TO DIE*, *supra* note 4, at § 4.06[A]. Furthermore, even if the advance directive were available and clearly addressed the situation at hand, it might not reflect the patient’s preferences. See, e.g., Henry S. Perkins, *Controlling Death: The False Promise of Advance Directives*, 147 *ANNALS INTERNAL MED.* 51, 53 (2007) (discussing that patient preferences often are compromised by poor proxy interpretation or from non-compliance with the advance directive by physicians). It is difficult for patients to anticipate their future preferences under new and different medical conditions. Therefore, instructional advance directives often fail to capture important preferences and priorities of patients. Consequently, clinical care may not be consistent with patient preferences. See, e.g., Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, *HASTINGS CENTER REP.*, Mar.-Apr. 2004, at 30, 38-39; Daniel P. Hickey, *The Disutility of Advance Directives: We Know the Problems, but Are There Solutions?*, 36 *J. HEALTH L.* 455, 459-60 (2003) (discussing the difficulties involved with completing advance directives); NICHOLAS A. CHRISTAKIS, *DEATH FORETOLD: PROPHECY AND PROGNOSIS IN MEDICAL CARE* 55 (1999) (explaining that advance directives “involve a sort of ‘hypothetical prognosis’”). On the other hand, better informed consent tools appear able to address some of these problems. See also Angelo E. Volandes et al., *Using Video Images to Improve the Accuracy of Surrogate Decision-Making: A Randomized Controlled Trial*, 10 *J. AM. MED. DIRECTORS ASS’N* 575, 578 (2009) (Surrogates receiving video decision support tool after verbal narrative made significantly better predications of what their loved ones would have wanted in an advanced dementia situation than those receiving only a verbal narrative.); Angelo E. Volandes et al., *Overcoming Educational Barriers for Advance Care Planning in Latinos with Video Images*, 11 *J. PALLIATIVE MED.* 700, 701 (2008) (studying the use of video images for improving advance care planning among Latinos).

158. See *RIGHT TO DIE*, *supra* note 4, at § 4.02[A]; *In re Estate of Longeway*, 549 N.E.2d at 299 (“Where no clear intent exists, the patient’s personal value system must guide the surrogate . . .”).

159. *AMA CODE OF ETHICS*, *supra* note 131, at 252.

This entails considering the patient's advance directive (if any), the patient's views about life and how it should be lived, how the patient has constructed his or her identity or life story, and the patient's attitudes towards sickness, suffering, and certain medical procedures.<sup>160</sup>

Alabama law similarly provides:

The surrogate shall consult with the attending physician and make decisions permitted herein that conform as closely as possible to what the patient would have done or intended under the circumstances, taking into account any evidence of the patient's religious, spiritual, personal, philosophical, and moral beliefs and ethics, to the extent these are known to the surrogate. Where possible, the surrogate shall consider how the patient would have weighed the burdens and benefits of initiating or continuing life-sustaining treatment . . . against the burdens and benefits to the patient of that treatment . . . .<sup>161</sup>

The law in other states is substantially similar.<sup>162</sup> Massachusetts, for example, provides: "[T]he agent shall make health care decisions . . . in accordance with the agent's assessment of the principal's wishes, including the principal's religious and moral beliefs . . . ." <sup>163</sup>

### 3. Best Interests Standard: Promote the Patient's Welfare

Sometimes, there is no reliable evidence of either the patient's expressed wishes or her values and preferences. In such cases, neither the subjective nor the substituted judgment standard can be applied. Therefore, the surrogate must shift her focus from the autonomy of the patient to the welfare of the patient.<sup>164</sup> In the absence of patient-centric evidence, the surrogate must rely on more objective grounds.<sup>165</sup> This decision-making

160. *Id.* If the advance directive specifically addresses the treatment at issue, then the surrogate would apply the subjective standard. But since advance directives are often not that clearly applicable, they often provide broad guidance rather than specific answers. *Id.* See also *id.* at 83 ("In making a substituted judgment, decision makers may consider the patient's advance directive (if any); the patient's values about life and the way it should be lived; and the patient's attitudes towards sickness, suffering, medical procedures, and death.").

161. ALA. CODE § 22-8A-11(c) (2006); see also *id.* § 22-8A-6.

162. See, e.g., MD. CODE ANN., Health-Gen. § 5-605(c)(1) (LexisNexis 2009); *In re Westchester Cnty. Med. Ctr.*, 531 N.E.2d 607, 619 (N.Y. 1988) ("[W]hen implementing substituted judgment . . . a surrogate . . . effectuates as nearly as possible the decision the incompetent would make if he or she were able to state it.") (internal citations omitted).

163. MASS. ANN. LAWS ch. 201D § 5 (LexisNexis 2009).

164. See, e.g., FLA. STAT. § 765.205(1)(b) (2009) ("If there is no indication of what the principal would have chosen, the surrogate may consider the patient's best interest . . . ."); MD. CODE ANN., Health-Gen. § 5-605(c)(1) (LexisNexis 2009) ("[I]f the wishes of the patient are unknown or unclear, [base decisions] on the patient's best interest.").

165. RIGHT TO DIE, *supra* note 4, at § 4.07[B].

criterion is referred to as the “best interest standard.”<sup>166</sup> The *Code of Medical Ethics* provides: “If there is no reasonable basis on which to interpret how a patient would have decided, the decision should be based on the *best interests* of the patient, or the outcome that would best promote the patient’s well-being.”<sup>167</sup>

The law across the United States is substantially similar. Massachusetts, for example, provides: “[I]f the principal’s wishes are unknown . . . the agent shall make health care decisions . . . in accordance with the agent’s assessment of the principal’s best interests.”<sup>168</sup> For example, even if we know little or nothing about what life-sustaining treatment a particular patient might have desired, we can still determine what the hypothetical reasonable person would want. Few individuals would want to be kept alive only to suffer from their underlying illness, especially where the treatment caused pain, side effects, indignity, embarrassment, frustration, and/or emotional suffering.<sup>169</sup> The *Code of Medical Ethics* more fully articulates the best interest standard:

Factors that should be considered when weighing the harms and benefits of various treatment options include the pain and suffering associated with treatment, the degree of and potential for benefit, and any impairments that may result from treatment.<sup>170</sup>

Other factors a surrogate might consider include: “(1) [the patient’s] physical, sensory, emotional, and cognitive functioning; (2) the quality of life, life expectancy and prognosis for recovery with and without treatment; (3) the various treatment options. . . (9) the degree of humiliation, dependence, and loss of dignity resulting from the condition and treatment. . . .”<sup>171</sup> In the futility context, “[a] patient’s preservable existence

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166. *Id.*

167. AMA CODE OF ETHICS, *supra* note 131, at 252 (emphasis added). See also *id.* at 83 (“If there is not adequate evidence of the incompetent patient’s preferences and values, the decision should be based on the best interests of the patient (what outcome would most likely promote the patient’s well-being).”).

168. MASS. ANN. LAWS ch. 201D § 5 (LexisNexis 2009) (also requiring “full consideration of acceptable medical alternatives”).

169. See *Woods v. Commonwealth of Ky.*, 142 S.W.3d 24, 35 (Ky. 2004) (discussing the factors that a court should consider when determining whether to withdraw life-sustaining treatment for an incapacitated person).

170. AMA CODE OF ETHICS, *supra* note 131, at 252; see also Frolik, *supra* note 141, at 71 (“The best-interests standard is in effect a signal of ‘best practices.’”).

171. See *Woods*, 142 S.W.3d at 35 (Ky. 2004). In a surprising application of the best interest test, the Kentucky Court of Appeals upheld the lower court’s ruling that it was in a patient’s best interest to donate a kidney to his brother because the patient was emotionally and psychologically dependent on him. *Strunk v. Strunk*, 445 S.W.2d 145, 146, 149 (Ky. Ct. App. 1969).



might be so tortuous, painful, or filled with suffering that it would be deemed inhumane for a surrogate to dictate continued medical intervention."<sup>172</sup> Even permanent unconsciousness is increasingly broadly recognized as a status in which a patient can derive zero benefit from continued LSMT.<sup>173</sup>

Notably, the Code specifically anticipates that surrogates might be guided by irrelevant concerns. It cautions: "One way to ensure that a decision using the best interest standard is not inappropriately influenced by the surrogate's own values is to determine the course of treatment that most reasonable persons would choose for themselves in similar circumstances."<sup>174</sup>

### III. UNFAITHFUL SURROGATES SHOULD BE REPLACED

While the use of surrogates is a key vehicle for promoting and protecting patients' prospective autonomy, surrogates are not always diligent and faithful agents.<sup>175</sup> Surrogates are frequently inaccurate in implementing patient preferences. Sometimes, they misinterpret or misapply the patient's instructions or wishes. Other times, they deliberately ignore patient instructions and preferences. Whether culpable or not, these unfaithful surrogates are violating the required decision-making standards. And they should be replaced.<sup>176</sup>

172. Norman L. Cantor, *Can Healthcare Providers Obtain Judicial Intervention Against Surrogates Who Demand "Medically Inappropriate" Life Support for Incompetent Patients?*, 24 CRITICAL CARE MED. 883, 884 (1996).

173. *Id.* at 884-85.

174. AMA CODE OF ETHICS, *supra* note 131, at 252 (emphasis added). See also JAMES L. BERNAT, ETHICAL ISSUES IN NEUROLOGY 89 (Lippincott Williams & Wilkins 2008) ("The best interest standard . . . attempts to be objective, [but] remains inherently subjective."); Frolik, *supra* note 141, at 61 ("How should the guardian choose . . . doing what the guardian might think is best based upon the values of the guardian . . . These can be eliminated as lacking any foundation in law."); *id.* at 70 ("[W]e can hardly expect them to ignore their own values, morality, and ethics in favor of what some mythical 'reasonable person' would do.").

175. See generally Robert S. Olick & Paul W. Armstrong, *Health Care Directives*, in 15B NEW JERSEY PRACTICE SERIES, LEGAL FORMS § 37:29 (4th ed. 2009) ("In practice the health care proxy will not always adequately represent the patient's interests.").

176. While this Article focuses on defending surrogate selection as an "option" for resolving some intractable futility disputes, there are other good reasons for surrogate selection. For example, complying with a maverick agent can expose the provider to liability. See, e.g., *Scheible v. Joseph L. Morse Geriatric Ctr.*, 988 So. (2d) 1130, 1131-32 (Fla. Dist. Ct. App. 2008); Kathleen E. Wherthey, *Cause of Action to Recover Damages for Health Care Provider's Failure to Comply with Advance Directive*, in 16 CAUSES OF ACTION 2d 83, 89 (2008); Holly Fernandez Lynch et al., *Compliance with Advance Directives: Wrongful Living and Tort Law Incentives*, 29 J. LEGAL MED. 133, 145 (2008) (discussing the case of Edward Winter).

### A. Surrogate Performance Is Mediocre

Unfortunately, surrogates often perform rather poorly.<sup>177</sup> Either (1) they do not know patient preferences or (2) they do not follow them.

#### 1. Surrogates Do Not Know Patient Preferences

Both the subjective standard and substituted judgment standard require that the surrogate make treatment decisions that reflect the patient's preferences and values. But surrogates, unfortunately, are often uninformed or misinformed about what the patient's treatment preferences and values actually are.

A number of empirical studies over the past few years confirm that the choices surrogates make for patients are often not the same choices that patients would make for themselves.<sup>178</sup> A recent meta-review of sixteen

177. K.A. Bramstedt, *Questioning the Decision-Making Capacity of Surrogates*, 33 INTERNAL MED. J. 257, 258 (2003).

178. See *id.*; Lauren G. Collins et al., *The State of Advance Care Planning: One Decade After SUPPORT*, 23 AM. J. HOSPICE & PALLIATIVE MED. 378, 379-80 (2006); Terri R. Fried et al., *Valuing the Outcomes of Treatment: Do Patients and Their Caregivers Agree?*, 163 ARCHIVES INTERNAL MED. 2073, 2077 (2003); Daniel S. Gardner & Betty J. Kramer, *End-of-Life Concerns and Care Preferences: Congruence among Terminally Ill Elders and their Family Caregivers*, 60 OMEGA 273 (2010); Sara M. Moorman & Deborah Carr, *Spouses' Effectiveness as End-of-Life Health Care Surrogates: Accuracy, Uncertainty, and Errors of Overtreatment or Undertreatment*, 48 GERONTOLOGIST 811, 818 ("Despite widespread reliance on spouses, our results show that surrogates are accurate in just 62% and 77% of cases, in pain and cognitive impairment scenarios, respectively."); Rachel A. Pruchno et al., *Predictors of Patient Treatment Preferences and Spouse Substituted Judgments: The Case of Dialysis Continuation*, 26 MED. DECISION MAKING 112, 119 (2006) (finding inaccurate substituted judgment because patients and surrogates used different criteria in formulating judgments about continuation of life-sustaining treatment and had different perceptions about the patients' conditions); William D. Smucker et al., *Modal Preferences Predict Elderly Patients' Life-Sustaining Treatment Choices as well as Patients' Chosen Surrogates Do*, 20 MED. DECISION MAKING 271, 276 (2000). See also RIGHT TO DIE, *supra* note 4, at § 3.16[C][2]; Magali Ciroidi et al., *Ability of Family Members to Predict Patient's Consent to Critical Care Research*, 33 INTENSIVE CARE MED. 807, 809 (2007); Michael Coppolino & Lynn Ackerson, *Do Surrogate Decision Makers Provide Accurate Consent for Intensive Care Research?*, 119 CHEST 603, 606-07 (2001); Nina A. Kohn & Jeremy A. Blumenthal, *Designating Health Care Decisionmakers for Patients Without Advance Directives: A Psychological Critique*, 42 GA. L. REV. 979, 996-997 (2008); Anand V. Mantravadi et al., *Accuracy of Surrogate Decision Making in Elective Surgery*, 33 J. CATARACT & REFRACTIVE SURGERY 2091, 2092 (2007). But see Linus Broström & Mats Johansson, *Surrogates Have Not Been Shown to Make Inaccurate Substituted Judgments*, 20 J. CLINICAL ETHICS 266, 266 (2009); Mats Johansson & Linus Broström, *Counterfactual Reasoning in Surrogate Decision Making—Another Look*, BIOETHICS (forthcoming 2010); Mats Johansson & Linus Broström, *Turning Failures into Successes: A Methodological Shortcoming in Empirical Research on Surrogate Accuracy*, 29 THEORETICAL MED. & BIOETHICS 17, 18 (2008) (addressing a methodological shortcoming evident in a significant number of studies on substitute decision-making).

studies indicated that, overall, surrogates predict patient's treatment preferences with just sixty-eight percent accuracy.<sup>179</sup> A more recent study found even lower accuracy.<sup>180</sup> Indeed, these are hardly new findings. This same dubious surrogate performance has been repeatedly measured and documented for over two decades.<sup>181</sup>

One aspect of these prediction studies is particularly notable for futility disputes. Not only do surrogates make inaccurate substituted judgments, but also that inaccuracy leans predominantly in one direction. Surrogate inaccuracy is strongly biased toward *overestimating* patient desires for treatment.<sup>182</sup> In other words, a surrogate is more likely to request aggressive

179. David I. Shalowitz et al., *The Accuracy of Surrogate Decision Makers: A Systematic Review*, 166 ARCHIVES INTERNAL MED. 493, 495 (2006) (Surrogate accuracy in dementia scenarios was only 58%).

180. Inés Maria Barrio-Cantalejo et al., *Advance Directives and Proxies' Predictions About Patients' Treatment Preferences*, 16 NURSING ETHICS 93, 105 (2009) ("The overall ability of the proxies in this study to predict the patients' preferences was . . . 62.83% . . .").

181. See Ezekiel J. Emanuel & Linda E. Emanuel, *Proxy Decision Making for Incompetent Patients: An Ethical and Empirical Analysis*, 267 JAMA 2067, 2069 (1992); Muriel Gillick et al., *A Patient-Centered Approach to Advance Medical Planning in the Nursing Home*, 47 J. AM. GERIATRICS SOC'Y 227, 228 (1999); Jan Hare et al., *Agreement Between Patients and Their Self-Selected Surrogates on Difficult Medical Decisions*, 152 ARCHIVES INTERNAL MED. 1049, 1049, 1052 (1992); Peter M. Layde et al., *Surrogates' Predictions of Seriously Ill Patients' Resuscitation Preferences*, 4 ARCHIVES FAM. MED. 518, 520-22 (1995); Joseph G. Ouslander et al., *Health Care Decisions Among Elderly Long-Term Care Residents and Their Potential Proxies*, 149 ARCHIVES INTERNAL MED. 1367, 1369-71 (1989); Robert A. Pearlman et al., *Spousal Understanding of Patient Quality of Life: Implications for Surrogate Decisions*, 3 J. CLINICAL ETHICS 114, 114, 117 (1992); Allison B. Seckler et al., *Substituted Judgment: How Accurate Are Proxy Predictions?*, 115 ANNALS INTERNAL MED. 92, 94-95 (1991) (discussing discrepancies between patients' end-of-life preferences and proxies' substituted judgment decision for patients); Jeremiah Suhl et al., *Myth of Substituted Judgment: Surrogate Decision Making Regarding Life Support Is Unreliable*, 154 ARCHIVES INTERNAL MED. 90, 93 (1994) (finding patient-surrogate agreement just 59.6% of the time); Daniel P. Sulmasy et al., *The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses*, 128 ANNALS INTERNAL MED. 621, 623 (1998); Nancy R. Zweibel & Christine K. Cassel, *Treatment Choices at the End of Life: A Comparison of Decisions by Older Patients and Their Physician-Selected Proxies*, 29 GERONTOLOGIST 615, 616, 618 (1989).

182. See Peter H. Ditto et al., *Advance Directives as Acts of Communication: A Randomized Controlled Trial*, 161 ARCHIVES INTERNAL MED. 421, 424 (2001); Hare et al., *supra* note 181, at 1051, 1052 (finding patient-surrogate agreement only seventy percent of the time); Pearlman et al., *supra* note 181, at 117, 119 tbls. 3 & 4; Shalowitz et al., *supra* note 179, at 495; Suhl et al., *supra* note 181, at 93-94; Richard F. Uhlmann et al., *Physicians' and Spouses' Predictions of Elderly Patients' Resuscitation Preferences*, 43 J. GERONTOLOGY M115, M117 (1988) (finding that spouses overestimated patients' preferences for resuscitation decisions, significantly so in some situations). See also SHARON KAUFMAN, *AND A TIME TO DIE: HOW HOSPITALS SHAPE THE END OF LIFE* 236-48 (2005); Laraine Winter & Susan M. Parks, *Family Discord and Proxy Decision Makers' End-of-Life Treatment Decisions*, 11 J. PALLIATIVE MED. 1109 (2008).

life-sustaining treatment for a patient than the patient would for herself.<sup>183</sup> Therefore, in many futility disputes, the treatment that surrogates request, and that providers want to refuse, is treatment that the patient probably does not even want.

None of this evidence is surprising given the widely observed failure of patients to discuss end-of-life planning with their prospective surrogates.<sup>184</sup> Patients themselves do not reflect on their end-of-life care, so it is unclear if they have even formed preferences to communicate to surrogates.<sup>185</sup> This is only exacerbated by the fact that patient preferences change over time.<sup>186</sup> In short, surrogates are presumed to be the best substitute decision makers for patients. But the available evidence seems to cast serious doubt on the basis for this presumption.

## 2. Surrogates Do Not Follow Patient Preferences

While surrogate knowledge of patient preferences is a necessary condition, it is hardly a sufficient condition for application of the subjective and substituted judgment standards. Surrogates must also be willing and able to make decisions on the basis of that knowledge. And, on the best interest standard, surrogates must be willing and able to make a decision on the basis of what will best promote the patient's well being. Unfortunately, surrogates are often not up to the challenge.<sup>187</sup> "We cannot ignore the

183. Laura Zettel-Watson et al., *Actual and Perceived Gender Differences in the Accuracy of Surrogate Decisions About Life-Sustaining Medical Treatment Among Older Spouses*, 32 DEATH STUDIES 273, 285-86 (2008) (Husbands committed "significantly more overtreatment errors than did wives acting as surrogates").

184. See Betty S. Black et al., *Surrogate Decision Makers' Understanding of Dementia Patients' Prior Wishes for End-of-Life Care*, 21 J. AGING & HEALTH 627, 629 (2009) (discussing studies finding that patients "were reluctant to think about, discuss, or plan for serious future illness"). See also Terri R. Fried et al., *Understanding Advance Care Planning as a Process of Health Behavior Change*, 57 J. AM. GERIATRICS SOC'Y 1547, 1547, 1552 (2009). On the other hand, some evidence suggests that this would not improve the rate of agreement. See Shalowitz, *supra* note 179, at 496.

185. See generally Louise Harmon, *Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1 (1990) (discussing cases in which patients had not reflected upon or communicated their choices for end-of-life care).

186. See Marion Danis, *Stability of Choices about Life-Sustaining Treatments*, 120 ANNALS INTERNAL MED. 567 (1994) (showing that 40% of patients who said they wanted life-sustaining treatments, said "no" to those treatments two years later); Marsha N. Wittink et al., *Stability of Preferences for End-of-Life Treatment After 3 Years of Follow-up*, 168 ARCHIVES INTERNAL MED. 2125, 2128-29 (2008) (discussing a study where preferences for life-sustaining treatment showed changes over time).

187. David Orentlicher, *The Limitations of Legislation*, 53 MD. L. REV. 1255, 1277-80 (1994); see also Kohn & Blumenthal, *supra* note 178, at 996-97. Physicians exacerbate this by asking surrogates what *they* want to do. Physicians should instead ask surrogates what the *patient* would have chosen. *Id.* at 1000-01.

possibility that a surrogate might act contrary to the wishes of the patient.”<sup>188</sup>

First, surrogates frequently do not understand the clinical status of the patients whom they represent.<sup>189</sup> “Less than half, regardless of educational level, had adequate knowledge of what was going on and what would happen [to the patient].”<sup>190</sup> Both for this reason and due to a belief in miracles, nearly ninety percent of surrogates doubt the physician’s prognosis.<sup>191</sup> But to accurately apply the patient’s wishes or determine best interests, the surrogate must comprehend the clinical information and the consequences of the options presented.

Second, many surrogates have clinically diagnosable conditions such as stress, depression, and anxiety.<sup>192</sup> These psychological problems may

188. *In re Browning*, 568 So. 2d 4, 15 (Fla. 1990).

189. Elizabeth A. Boyd et al., “It’s Not Just What the Doctor Tells Me” Factors that Influence Surrogate Decision Makers’ Perceptions of Prognosis, 38 *CRITICAL CARE MED.* 1270 (2010); Susan J. Lee Char et al., A Randomized Trial of Two Methods to Disclosing Prognosis to Surrogate Decision Makers in Intensive Care Units, 182 *AM. J. RESPIRATORY & CRITICAL CARE MED.* 905, 909 (2010) (“[S]urrogates prognostic estimates were on average more than twice as optimistic as the physician’s prognostic estimate.”); Robert M. Rodriguez et al., A Prospective Study of Primary Surrogate Decision Makers’ Knowledge of Intensive Care, 36 *CRITICAL CARE MED.* 1633, 1633, 1635 (2008) (finding only fifty percent of surrogates had a “good” understanding of the patient’s care); Margaret L. Rothman et al., *The Validity of Proxy Generated Scores as Measures of Patient Health Status*, 29 *MED. CARE* 115 (1991).

190. James W. Jones & Lawrence B. McCullough, *Dominions of Surrogate Opinions: Who Is in Charge?*, 49 *J. VASCULAR SURGERY* 249, 249 (2009).

191. Lucas S. Zier et al., *Doubt and Belief in Physicians’ Ability to Prognosticate During Critical Illness: The Perspective of Surrogate Decision Makers*, 36 *CRITICAL CARE MED.* 2341, 2342-43 (2008).

192. See generally Elie Azoulay et al., *Risk of Post-Traumatic Stress Symptoms in Family Members of Intensive Care Unit Patients*, 171 *AM. J. RESPIRATORY & CRITICAL CARE MED.* 987, 989-91 (2005) (finding many family members of critically ill patients experience post-traumatic stress reactions and/or symptoms of anxiety and depression); Lauris C. Kaldjian et al., *Dementia Goals of Care and Personhood: A Study of Surrogate Decision Makers’ Beliefs and Values*, \_\_ *AM. J. HOSPICE & PALLIATIVE MED.* (forthcoming 2010); Virginia Lemiale et al., *Health Related Quality of Life in Family Members of ICU Patients*, 13 *J. PALLIATIVE MED.* 1131 (2010); Jennifer McAdam et al., *Symptom Experiences of Family Members of ICU Patients at High Risk of Dying*, 38 *CRITICAL CARE MED.* 1078 (2010); Jennifer L. McAdam & Kathleen Puntillo, *Symptoms Experienced by Family Members of Patients in Intensive Care Units*, 18 *AM. J. CRITICAL CARE* 200, 203-04 (2009) (discussing prevalence rates of traumatic stress levels, depression, and anxiety in family members of patients in intensive care); Marie Cécile Poncet et al., *Burnout Syndrome in Critical Care Nursing Staff*, 175 *AM. J. RESPIRATORY & CRITICAL CARE MED.* 698, 698, 701-02 (2007) (discussing how stress can cause burnout syndrome for nurses involved with making end-of-life decisions); Frédéric Pochard et al., *Symptoms of Anxiety and Depression in Family Members of Intensive Care Unit Patients Before Discharge or Death: A Prospective Multicenter Study*, 20 *J. CRITICAL CARE* 90, 93-94 (2005) (discussing prevalence of symptoms of anxiety and depression in family members and spouses of ICU patients); Frédéric Pochard et al., *Symptoms of Anxiety and Depression in Family Members of*

impair the surrogate's own decision-making capacity.<sup>193</sup> The surrogate may "fail to exercise sound and informed judgment, or will find it too difficult to accept personal responsibility for carrying out the patient's wishes."<sup>194</sup> In short, "a serious question arises about the surrogate's fitness to serve."<sup>195</sup>

Third, surrogates often "cannot distinguish their own preferences from those of the patient."<sup>196</sup> There are two leading psychological explanations for this tendency. Surrogates may act on "assumed similarity" by assuming that she and the patient hold similar preferences and thus allowing her own preferences to guide the decision.<sup>197</sup> Surrogates may also be affected by "projection bias," because they have difficulty disregarding their current preferences formed under current circumstances even though they are irrelevant both to the patient and to the patient's condition.<sup>198</sup>

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*Intensive Care Unit Patients: Ethical Hypothesis Regarding Decision-Making Capacity*, 29 CRITICAL CARE MED. 1893, 1894, 1896 (2001) (discussing prevalence of symptoms of anxiety and depression, and risk of posttraumatic stress disorder in family members of ICU patients); Mark D. Siegel et al., *Psychiatric Illness in the Next of Kin of Patients Who Die in the Intensive Care Unit*, 36 CRITICAL CARE MED. 1722, 1725-27 (2008) (discussing how many next of kin of patients in ICU have major depression or other psychiatric illnesses); Erika K. Tross et al., *Care Associated with Symptoms of Depression and PTSD among Family Members of those Who Die in the ICU*, \_\_ CHEST (forthcoming 2010); Virginia P. Tilden et al., *Family Decision-Making to Withdraw Life-Sustaining Treatments from Hospitalized Patients*, 50 NURSING RES. 105, 112-13 (2001) (discussing stress levels of family members making decisions to withdraw treatments).

193. See RIGHT TO DIE, *supra* note 4, at §3.17. See also Prendergast, *supra* note 113, at 66-67 (discussing why fiduciaries should intercede in situations where surrogates insist on continued care even when it conflicts with the patient's interests and does not improve the patient's health).

194. Olick & Armstrong, *supra* note 175, at § 37:29.

195. RIGHT TO DIE, *supra* note 4, at §3.24[C][2].

196. Moorman & Carr, *supra* note 178, at 812. See also Yoram Bar-Tal et al., *Whose Informational Needs Are Considered? A Comparison Between Cancer Patients and Their Spouses' Perceptions of Their Own and Their Partners' Knowledge and Informational Needs*, 60 SOC. SCI. & MED. 1459, 1461-64 (2005); Collins et al., *supra* note 178, at 379; Angela Fagerlin et al., *Projection in Surrogate Decisions About Life-Sustaining Medical Treatments*, 20 HEALTH PSYCH. 166, 167-69, 171, 173 (2001); Melissa A. Z. Marks & Hal R. Arkes, *Patient and Surrogate Disagreement in End-of-Life Decisions: Can Surrogates Accurately Predict Patients' Preferences?*, 28 MED. DECISION MAKING 524, 529 (2008) ("[W]hen surrogates must make difficult, end-of-life decisions for a loved one . . . their wishes for the patient tend to enter into surrogates' predictions of patients' preferences . . . . [S]urrogates often are unable to discriminate between what they want for the patient and what the patient would want for himself or herself."); Rachel A. Pruchno et al., *Spouse as Health Care Proxy for Dialysis Patients: Whose Preferences Matter?*, 45 GERONTOLOGIST 812, 816-17 (2005); Rebecca Sudore & Terri R. Fried, *Redefining the 'Planning' in Advance Care Planning: Preparing for End-of-Life Decision Making*, 153 ANNALS INTERNAL MED. 256, 256 (2010) ("Surrogates may use their own hopes, desires, and needs to inform their decisions.") (collecting cites).

197. Sara M. Moorman et al., *Do Older Adults Know Their Spouses' End-of-Life Treatment Preferences?*, 31 RES. ON AGING 463, 466 (2009).

198. *Id.* at 466-67, 482.

Fourth, surrogates may base their decisions on factors external to the patient.<sup>199</sup> They may have “dubious motives” in that they are looking out for their own interests rather than the patient’s interests.<sup>200</sup> Some surrogates make decisions to avoid the guilt from making a death-hastening decision or to avoid criticism from other family members as having made the decision.<sup>201</sup> Other surrogates make deliberately and intentionally selfish decisions.<sup>202</sup>

199. This non-patient focus obtains outside the futility context, for example, where surrogates make decisions: (i) to involve the patient in experimental treatment that holds no benefit to the patient, (ii) to donate the patient’s organs, or (iii) to harvest the patient’s gamete material where there is no evidence that the patient planned to procreate. While sometimes permissible, such decisions are presumptively disallowed. See Cornelia Beck & Valorie Shue, *Surrogate Decision-Making and Related Issues*, 17 ALZHEIMER DISEASE & ASSOCIATED DISORDERS S12, S13, S15 (2003) (discussing (i) experimental treatment that holds no benefit to the patient); Marcia Sue DeWolf Bosek, *Organ Donation and Surrogate Decision-Making: An Ethical Analysis*, 8 J. NURSING ADMIN. HEALTHCARE L., ETHICS, & REG. 38, 38 (2006) (discussing (ii) surrogate decisions regarding organ donation); Frances R. Batzer et al., *Postmortem Parenthood and the Need for a Protocol with Posthumous Sperm Procurement*, 79 FERTILITY & STERILITY 1263, 1265 (2003) (discussing (iii) surrogate decisions regarding postmortem gamete procurement). Cf. Fine, *supra* note 115, at 1558 (“[N]ever use a patient as a means to the family’s end.”).

200. Fine, *supra* note 115, at 1558. See, e.g., BERNAT, *supra* note 174, at 93 (“Conflicts of interest can occur when the surrogate’s decision is made more in her own interest than in the patient’s interest. Equally disturbing are the reports of cases in which the surrogate has chosen a course of treatment or non-treatment that is diametrically opposite the one which the physician understood the patient to want when the patient was competent.”); Ann Alpers & Bernard Lo, *Avoiding Family Feuds: Responding to Surrogate Demands for Life-Sustaining Interventions*, 27 J.L. MED. & ETHICS 74, 74, 76-77 (1999); Muriel R. Gillick & Terri Fried, *The Limits of Proxy Decision Making: Undertreatment*, 4 CAMBRIDGE Q. HEALTHCARE ETHICS 172, 172-73 (1995); John Hardwig, *The Problem of Proxies with Interests of Their Own: Toward a Better Theory of Proxy Decisions*, 4 J. CLINICAL ETHICS 20, 20-21 (1993); John Arthur McClung, *Time and Language in Bioethics: When Patient and Proxy Appear to Disagree*, 6 J. CLINICAL ETHICS 39, 39, 42-43 (1995); Olick & Armstrong, *supra* note 175, at § 37:29 (“Some may find following the patient’s wishes contrary to the dictates of personal morality or conscience.”); Jeffrey Spike & Jane Greenlaw, *Ethics Consultation: Refusal of Beneficial Treatment by a Surrogate Decision Maker*, 23 J.L. MED. & ETHICS 202, 203-04 (1995); Peter B. Terry et al., *End-of-Life Decision Making: When Patients and Surrogates Disagree*, 10 J. CLINICAL ETHICS 286, 290, 292 (1999).

201. See *A Tale of Two Patients*, <http://urostream.blogspot.com/2007/11/tale-of-two-patients.html> (Nov. 10, 2007, 11:25 AM) (“[N]obody wants to be accused [of] ‘killing off’ grandma or grandpa.”).

202. See Olick & Armstrong, *supra* note 175, at § 37:29 (“In rare cases the proxy will act on the basis of improper or selfish motivations, financial or otherwise—the classic example is the family member driven by the prospect of inheriting substantial wealth.”); LORI A. STIEGEL & ELLEN VANCLEAVE KLEM, AARP PUB. POLICY INST., *POWER OF ATTORNEY ABUSE: WHAT STATES CAN DO ABOUT IT: A COMPARISON OF CURRENT STATE LAWS WITH THE NEW UNIFORM POWER OF ATTORNEY ACT 4* (2008); see *infra* notes 331 to 362.

### 3. Formalized Distrust of Surrogates

There has long been a tension between the quick and easy identification of surrogates, on the one hand, and the inclusion of cumbersome procedural safeguards, on the other hand.<sup>203</sup> Today, the balance has been struck in favor of quick and easy identification.<sup>204</sup> There are no “rigorous procedures” for patient- and physician-designated surrogates precisely because “they were enacted primarily to avoid the expense of full guardianship or conservatorship proceedings.”<sup>205</sup>

Still, recognizing the deficiencies of surrogate decision-making, most states have various special limitations on consent by surrogates.<sup>206</sup> There is perhaps no better example of the formalized distrust of surrogates than the U.S. Supreme Court’s *Cruzan* decision.<sup>207</sup> The court held that the U.S. Constitution permitted Missouri to impose a “procedural safeguard” requiring the surrogate to have clear and convincing evidence of the patient’s wishes.<sup>208</sup> The court was concerned that the views of a surrogate would not “necessarily be the same as that patient’s would have been had she been confronted with. . . her situation while competent.”<sup>209</sup>

Because the patient herself specifically chooses them, agents are accorded greater trust. They are often given more discretion than physician- or court-designated surrogates.<sup>210</sup> For example, often only patient-selected

203. See generally Karna Halverson, *Voluntary Admission and Treatment of Incompetent Persons with a Mental Illness*, 32 WM. MITCHELL L. REV. 161, 172-74 (2005) (discussing different approaches for identifying surrogates, and the statutes used to simplify the process or create safeguards).

204. Cf. *id.* at 187 (discussing the inflexibility of consent laws and suggesting revisions that “would permit family or friends to consent to treatment of an incompetent patient”).

205. PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOEMED. & BEHAVIORAL RES., DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 147 (1983), quoted in SABATINO, *supra* note 129, at 9, 28 (“The judiciary has had neither the resources nor the expertise for taking on responsibility in all such cases.”).

206. See SABATINO, *supra* note 129, at 28-29 (“Only eight states follow the Uniform Health-Care Decisions Act model that places no limitations on default surrogates.”); Abigail Petersen, *Survey of States’ Health Care Decision-Making Standards*, 28 BIFOCAL 53, 61-64 (2007) (listing types of limitations); A.M. v. Benes, [1999] CanLII 3807 [11] (ON C.A.) (Rejecting a “good faith” test for surrogates, the Ontario Court of Justice explained such a test would “fail to screen out the results of rank stupidity, or carelessness, or well-meant fanaticism or palpable illusion.”).

207. *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261 (Mo. 1990).

208. *Id.* at 280.

209. *Id.* at 286-87.

210. See, e.g., *S.I. v. R.S.*, 877 N.Y.S.2d 860, 866 (Supp. 2009) (“Petitioners have failed to establish any ground upon which the agent should be removed, they have not established that the agent is acting in bad faith; nor have they proffered any proof that would warrant overriding the agent’s decision on the grounds that the decision was made in bad faith or that it was not in accordance with PHL § 2982(1) or (2). Mere speculation or hope, regardless of



surrogates can (a) refuse life-sustaining treatment even when the patient is in a terminal condition or permanently unconscious,<sup>211</sup> (b) refuse artificial nutrition and hydration,<sup>212</sup> or (c) in New York (before June 2010), refuse life-sustaining interventions other than CPR.<sup>213</sup>

But most surrogates are not patient-designated. And *Cruzan* is hardly the only example of the limitations of such surrogates. For example, in *Wendland*, the California Supreme Court held that the patient's wife and court-appointed conservator did not have the authority to consent to the removal of his life-sustaining medical treatment.<sup>214</sup> Had the patient been in a persistent vegetative state instead of a minimally conscious state, the wife would have had that authority.<sup>215</sup> This illustrates a general inverse correlation rule: The better off the patient, the narrower the scope of surrogate authority.<sup>216</sup>

Unfortunately, these safeguards are usually designed to work in only one direction, like installing a railing on only one side of a pedestrian bridge. Specifically, the safeguards ensure that surrogates only consent to the withholding and withdrawing of treatment in accordance with patient wishes or best interests. They focus far less on assuring that surrogate consent to *continuing* treatment is in accordance with patient wishes or best interests.

#### 4. Summary

The vehicles for promoting and protecting patients' prospective autonomy are imperfect. Still, the benefits of surrogate decision-making outweigh its risks. While substituted judgment has its problems, other

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how heartfelt, can not override the agent's decisions, which have priority over other surrogates."'). Still, not even agents can consent to some interventions. See, e.g., CAL. PROB. CODE § 4711 (West 2009).

211. See, e.g., ALASKA STAT. § 13.52.030 (2008); DEL. CODE ANN. tit. 16, § 2507 (2003); 755 ILL. COMP. STAT. 40/1-65 (2008); LA. REV. STAT. ANN. §§ 40:1299.58.1-1299.58.10 (2008); ME. REV. STAT. ANN. tit. 18-A, §§ 5-801-817 (1998); N.C. GEN. STAT. § 90-322 (2009); OHIO REV. CODE ANN. § 2133.08 (West 2005).

212. See, e.g., KY. REV. STAT. ANN. § 311.629 (LexisNexis 2007); OHIO REV. CODE ANN. § 2133.09 (West 2005).

213. See Pope, *supra* note 133, at 362-63 (2009) (discussing how a New York law will allow surrogates to make additional life-sustaining treatment decisions).

214. *Wendland v. Wendland*, 28 P.3d 151, 154, 174-75 (Cal. 2001).

215. See *id.* at 175 (The holding "does not affect permanently unconscious patients, including those who are comatose or in a persistent vegetative state.").

216. See generally *In re Conroy*, 486 A.2d 1209 (N.J. 1985) (discussing limitations on surrogate authority when the patient is "not brain dead, comatose, or in a chronic vegetative state").

standards have problems of their own.<sup>217</sup> Surrogates, after all, are still more accurate than physicians.<sup>218</sup> And even if no decision were made on the patient's behalf, we would still have to determine a status quo. That would itself constitute a decision made for the patient, indeed, one that may not reflect the patient's own preferences and values.

Consequently, I have reviewed this empirical evidence on surrogate decision-making not to suggest that we should not have surrogates. Rather, I provide this background for context. Knowing surrogate deficiencies should make us less reluctant to replace surrogates in those situations, at the margins, where a presumption can be rebutted that the surrogate is acting pursuant to the required decision-making standards.<sup>219</sup>

217. See Linus Broström & Mats Johansson, *A Virtue-Ethical Approach to Substituted Judgment*, 25 ETHICS & MED. 107, 107-08 (2009), citing ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* 112-26 (1989).

218. See, e.g., Kristen M. Coppola et al., *Accuracy of Primary Care and Hospital-Based Physicians' Predictions of Elderly Outpatients' Treatment Preferences With and Without Advance Directives*, 161 ARCHIVES INTERNAL MED. 431, 435 (2001); G.S. Fischer et al., *Patient Knowledge and Physician Predictions of Treatment Preferences after Discussion of Advance Directives*, 13 J. GEN. INTERNAL MED. 447 (1998); Seckler et al., *supra* note 181, at 94, 95; Uhlmann et al., *supra* note 182, at M117. Physicians tend to base their decision on a subjective assessment of the patient's quality of life that is less favorable than the patient's own assessment. See Robert A. Pearlman & Richard F. Uhlmann, *Quality of Life in Chronic Diseases: Perceptions of Elderly Patients*, 43 J. GERONTOLOGY M25, M27-28 (1988).

219. Making it too easy for a physician to challenge a surrogate would open the door to unjustified paternalism, where "someone who does not agree with a physicians [sic] recommendation might be thought to have 'questionable motives.'" Letter from John Doherty, Directing Attorney, AIDS Legal Servs., to Stan Ulrich, Assistant Executive Sec'y, Cal. Law Revision Comm'n (Nov. 29, 1999) (on file with the Cal. Law Revision Comm'n as Study L-4003: Second Supplement to Memorandum 99-82). In one study, thirteen percent of physicians reported that they and the surrogate disagreed "about the right thing to do." Torke et al., *Physicians' Experience with Surrogate Decision Making for Hospitalized Adults*, 24 J. GEN. INTERNAL MED. 1023, 1026 (2009). Just as judges cannot and should not disregard all jury findings with which they disagree, hardly all of these surrogates can or should be replaced. Physicians must generally comply with the surrogate's reasonable interpretation of the patient's advance directive. See, e.g., DEL. CODE ANN. tit. 16, § 2508(d)(1) (2003). This limits the scope of the physician to simply select a surrogate who agrees with the physician's recommendation. Cal. Law Revision Comm'n Staff Memorandum 98-63: Health Care Decisions: Comments on Tentative Recommendation 4 (Sept. 18, 1998) (on file with the Cal. Law Revision Comm'n). "Reliance on surrogate decisions seems inescapable." Daniel P. Sulmasy et al., *The Accuracy of Substituted Judgment in Patients with Terminal Diagnoses*, 128 ANNALS INTERNAL MED. 621, 629 (1998).

### B. *Rationale for Surrogate Replacement*

Surrogates are generally obligated to make health care decisions in accordance with the patient's preferences and best interests.<sup>220</sup> Particularly for a conscious or semi-conscious patient, continuing LSMT contrary to provider recommendations often contravenes patient preferences and/or best interests. Consequently, surrogates who make such requests are often acting outside the scope of their authority and should be replaced with other decision makers.<sup>221</sup> The *Code of Medical Ethics* advises:

Though the surrogate's decision for the incompetent patient should almost always be accepted by the physician, there are four situations that may require either institutional or judicial review and/or intervention in the decision-making process: . . . (3) a health care provider believes that the family's decision is clearly not what the patient would have decided if competent; and (4) a health care provider believes that the decision is not a decision that could reasonably be judged to be in the patient's best interests.<sup>222</sup>

220. See generally *RIGHT TO DIE*, *supra* note 4, at §§ 4.01-4.10 (discussing incompetent patients and surrogacy); DEP'T OF VETERANS AFFAIRS, VETERANS HEALTH ADMINISTRATION HANDBOOK 1004.01: INFORMED CONSENT FOR CLINICAL TREATMENTS AND PROCEDURES 14b.(1)(c) (2009) ("The surrogate's decision must be based on substituted judgment or, if the patient's values and wishes are unknown, on the patient's best interests . . . If the practitioner considers the surrogate to be clearly acting contrary to the patient's values and wishes or the patient's best interests, the practitioner must notify the Chief of Staff, or designee, and consult with the local Integrated Ethics program officer or Regional Counsel . . ."). Cf. *In re Orshansky*, 804 A.2d 1077, 1081, 1103 (D.C. 2002) (discussing a situation where a health care proxy is trying to make health care decisions in the best interest of the patient).

221. See BERNAT, *supra* note 174 at 189 (arguing for judicial recourse "when there is evidence that a surrogate is deciding for reasons that are not altruistic"); Cantor, *supra* note 172, at 885 ("Courts should be willing to curb surrogates' unexplained deviations from a course widely understood to be consistent with a patient's best interests and likely wishes."); Gerald Kierzek et al., *Advance Directives and Surrogate Decision Making before Death*, 363 NEW ENG. J. MED. 295, 295 (2010) (rightly being "surprised by the [de facto] authority of a surrogate to override all decisions even when surrogate decisions are inconsistent with the patient's written preferences"); Bernard Lo et al., *The Wendland Case—Withdrawing Life Support from Incompetent Patients Who Are Not Terminally Ill*, 346 NEW ENG. J. MED. 1489, 1491-92 (2002) ("The assumption that the spouse should be the surrogate decision maker can be overturned—for example, if the couple has separated or if there has been domestic violence. Also, physicians should not follow a spouse's decision if it contradicts previously expressed wishes of the patient that are so specific and to the point that they would meet the legal standard of clear and convincing evidence."); Mark R. Tonelli, *Withdraw Life Support on the Basis of Substituted Judgment*, 360 NEW ENG. J. MED. 530, 530 (2009) ("The choices of legal surrogates do not necessarily represent substituted judgments, nor should substituted judgments be taken at face value. Due diligence is required to ascertain whether a substituted judgment seems to be a valid expression of a patient's previously held goals and values.").

222. AMA CODE OF ETHICS, *supra* note 131, § 2.20.

An appellate court similarly observed that when a surrogate insists on inappropriate treatment “the usual procedure . . . is to . . . go to court to replace the surrogate or override his decision.”<sup>223</sup>

For example, surrogate selection was a major issue in the *Schiavo* case. Michael Schiavo was the surrogate for his wife Terri.<sup>224</sup> He instructed providers to remove her feeding tube because Terri would not have wanted to remain in a persistent vegetative state.<sup>225</sup> Terri’s parents challenged Michael and argued that he was an unfit surrogate.<sup>226</sup> However, they also indicated that they would insist Terri be given treatment even if she had provided clear directives otherwise.<sup>227</sup> They thereby “disqualified themselves from ever being appointed proxies. . . . because they had declared that they would ignore the fundamental ethical and legal requirements of a proper surrogate.”<sup>228</sup>

Many state statutes specifically provide for surrogate replacement.<sup>229</sup> Massachusetts, for example, provides that a “health care provider . . . may

223. *Causey v. St. Francis Med. Ctr.*, 719 So. 2d 1072, 1076 n.3 (La. Ct. App. 1998). In addition to the argument that the surrogate is not fulfilling his or her statutorily-provided role, the court observed that surrogate selection would be appropriate where “the guardian or surrogate is guilty of abuse by insisting on care which is inhumane.” *Id.*

224. *In re Schiavo*, 780 So. 2d 176, 177 (Fla. Dist. Ct. App. 2001). See also C. Christopher Hook & Paul S. Mueller, *The Terri Schiavo Saga: The Making of a Tragedy and Lessons Learned*, 80 MAYO CLINIC PROC. 1449, 1450 (2005).

225. *In re Schiavo*, 780 So. 2d at 178, 180 (“Her statements to her friends and family about the dying process were few and they were oral. Nevertheless, those statements . . . gave the trial court sufficient basis to made the decision for her.”); Hook & Mueller, *supra* note 224, at 1450.

226. *In re Schiavo*, 780 So. 2d at 178-80. See also Hook & Mueller, *supra* note 224, at 1450-51 (discussing how the Schindlers disagreed with Michael’s decision to remove Terri’s feeding tube, and how the court appointed a second guardian ad litem to better serve Terri’s interests).

227. Hook & Mueller, *supra* note 224, at 1451, 1455.

228. *Id.* at 1455.

229. See, e.g., ALASKA STAT. § 13.52.030 (2008) (discussing circumstances when the primary health provider may decline to comply with a surrogate decision and notify the appropriate health care institution); DEL. CODE ANN. tit. 16, § 2511 (2003) (discussing circumstances when the Court of Chancery can be petitioned for appointment of a guardian); MASS. ANN. LAWS ch. 201D, § 17 (LexisNexis 1994) (discussing circumstances when a special court proceeding can be commenced to override an agent’s decision); N.Y. PUB. HEALTH LAW § 2992 (McKinney 2007) (discussing circumstances when a special court proceeding can be commenced to remove an agent or override an agent’s decision); OHIO REV. CODE ANN. § 2133.08 (West 2005) (discussing circumstances when a court hearing can be held to determine whether a surrogate decision should be confirmed or reversed); TEX. HEALTH & SAFETY CODE 166.039(g) (providing that any person in a class of default surrogates can apply for temporary guardianship to challenge the decision of the designated surrogate). Cf. Thomas J. Balch, *Are There Checks and Balances on Terminating the Lives of Children with Disabilities*, 25 GA. ST. U. L. REV. 959, 967 n.32 (2009). In a related context, the Revised

commence a special proceeding . . . [to] override the agent's decision about health care treatment on the grounds that: the decision was made in bad faith or the decision is not in accordance with [the decision-making] standards."<sup>230</sup> Florida similarly permits a provider to seek "an expedited judicial intervention" if the provider believes the surrogate's decision is not in accord with the patient's known desires or best interests.<sup>231</sup>

While other states provide no special judicial mechanism with which to replace surrogates, they do clearly and firmly state that surrogates acting inconsistently with specified decision-making standards do not have authority to speak for the patient. The Delaware Healthcare Decisions Act, for example, provides that healthcare providers should "comply with health-care decisions for the patient made by a person then authorized to make health-care decisions for the patient *to the extent* the agent or surrogate is permitted."<sup>232</sup>

### C. Method of Surrogate Replacement

"When the surrogate seems to be making choices not in accordance with the patient's best interest, it is up to the treating physician to confirm that the surrogate is deciding in accordance with the patient's stated preferences or known values."<sup>233</sup> But because the informal resolution of futility disputes is so often successful, providers should exhaust such mechanisms before taking formal action to replace the surrogate.<sup>234</sup> After

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Uniform Anatomical Gift Act, now adopted in most states, precludes family members from overriding donor consent to organ donation. See Thaddeus Mason Pope, *Legal Briefing: Organ Donation and Allocation*, 21 J. CLINICAL ETHICS 243 (2010).

230. MASS. ANN. LAWS ch. 201D, § 17 (LexisNexis 1994). See also N.Y. PUB. HEALTH LAW § 2992 (McKinney 2007) (discussing similar circumstances when a special court proceeding can be commenced to remove an agent or override an agent's decision).

231. FLA. STAT. ANN. §§ 765.105(1), 765.205(1)(b) (West 2005).

232. DEL. CODE ANN. tit. 16, § 2508(d)(2) (2003) (emphasis added).

233. Kathryn J. Rowland et al., *Surgical Futility: "Aggressive" Surgery on the Severely Demented*, 145 SURGERY 351, 353 (2009).

234. See Franz-Josef Illhardt, *Conflict Between a Patient's Family and the Medical Team*, 19 HEALTHCARE ETHICS COMMITTEE FORUM 381, 383 (2007) ("An initial subject raised . . . was the feasibility of having the power-of-attorney withdrawn from the daughter, since it had become obvious that she was acting more in her own than in her mother's interest. But was that really so?"); *id.* at 386 (concluding that consensus can often be reached by: (i) allowing the surrogate to adapt to her role, (ii) educating the surrogate about her role, and (iii) and making sure that the surrogate understands the clinical information); Meisel & Jennings, *supra* note 136, at 76 (explaining that most surrogates initially opposed to stopping LSMT "ultimately agree to its termination"). See generally Pope & Waldman, *supra* note 11. In one recent case, the court rejected an attempt at surrogate selection before consensus building efforts had been attempted. *In re DP*, 2010 CanLII 42949 (Ont. C.C.B.) (dismissing Form G Application).

all, being a surrogate is not an easy job.<sup>235</sup> Illogical thinking might not reflect a careless, reckless, or malicious surrogate, but rather an uninformed or emotionally burdened surrogate.

In one recently published account, a nursing home called a resident's surrogate. "Your aunt has lower gastrointestinal bleeding. Do you want us to send her to the hospital?"<sup>236</sup> The surrogate said she that would discuss it with her husband and call back.<sup>237</sup> The surrogate soon decided to send her aunt to the hospital.<sup>238</sup> But then, just as she was walking to the kitchen to return the call, the surrogate heard her aunt's familiar refrain from recent months: "Pray for me to die."<sup>239</sup> The surrogate explained, "I knew if the decision were hers to make she would refuse to go to the hospital. I called the nursing home and told staff not to send her."<sup>240</sup>

In another recent account, the physician explained to the surrogate that her "father's heart [was] weak, his kidneys [were] failing, and his lungs [were] filling with fluid."<sup>241</sup> The physician then asked, "Does your father want us to employ extreme measures . . . ?"<sup>242</sup> The surrogate was conflicted.<sup>243</sup> She wanted to "stop the insane cycle of hospitalizations and heroic life-saving treatments" that were not helping her father: "He is dying. And I am exhausted . . . . I want my life back."<sup>244</sup> The surrogate was "acutely tempted to answer [no]."<sup>245</sup> But she instead gave the physician the answer that she knew to be true, even though both she and the physician thought it unreasonable.<sup>246</sup>

While these two surrogates were faithful, their decisions were hard. Surrogates are performing a new role, for the first time, under difficult circumstances. Therefore, healthcare providers should make every effort to

235. See, e.g., Hannah I. Lipman, *Surrogate Decision Making*, 17 AM. J. GERIATRIC CARDIOLOGY 120 (2008); *His Last Wish: Carrying Out End-of-Life Requests Not a Simple Matter*, FOSTERS.COM, Feb. 1, 2009, [http://www.fosters.com/apps/pbcs.dll/article?AID=/20090201/GJCOMMUNITY\\_01/702019855](http://www.fosters.com/apps/pbcs.dll/article?AID=/20090201/GJCOMMUNITY_01/702019855) (detailing a surrogate's difficult decision not to pursue bypass surgery for a 75-year-old with lymphoma and dementia).

236. Louise Szabo, *My Aunt's Life Was in My Hands*, GLOBE & MAIL, Jan. 21, 2010, <http://www.theglobeandmail.com/life/facts-and-arguments/my-aunts-life-was-in-my-hands/article1438216>.

237. *Id.*

238. *Id.*

239. *Id.*

240. *Id.*

241. Alicia von Stamwitz, *An Ill Father, a Life-or-Death Decision*, N.Y. TIMES, Jan. 26, 2010, at D5, available at <http://www.nytimes.com/2010/01/26/health/26case.html>.

242. *Id.*

243. *Id.*

244. *Id.*

245. *Id.*

246. See *id.*

clarify the situation.<sup>247</sup> Specifically, they should do two things. First, they should advise the surrogate of the “duties of a good surrogate decision maker.”<sup>248</sup> Second, they should make sure that the surrogate understands the prognostic information about the patient.<sup>249</sup>

If good communication about prognosis and the role of surrogates does not work, mediation often works. The *Code of Medical Ethics* advises that “[w]hen a physician believes that a decision is clearly not what the patient would have decided, could not be reasonably judged to be within the patient’s best interests, or primarily serves the interest of a surrogate or a third party, an ethics committee should be consulted before requesting court intervention.”<sup>250</sup>

Usually, conflict will “dissipate when communication improves, misunderstandings are corrected, and emotional and spiritual needs are met.”<sup>251</sup> While surrogate replacement may be an option for some intractable disputes, most futility disputes will not become intractable.

247. See, e.g., See David E. Weissman et al., *Helping Surrogates Make Decisions*, FAST FACTS AND CONCEPTS (2010), [http://www.mcw.edu/fastFact/FF\\_226](http://www.mcw.edu/fastFact/FF_226).

248. See Braun et al., *supra* note 69, at 252 (“To reduce this burden [of decision], the physician should point out that the decision has already been made—by the patient. The task at hand is to respect and implement the patient’s decision.”); AMA CODE OF ETHICS, *supra* note 131, § 2.20 (“Physicians should . . . explain to surrogate decision makers that decisions regarding withholding or withdrawing life-sustaining treatment should be based on substituted judgment (what the patient would have decided) . . . .”); Viki Kind, *Helping the Family Make the Difficult Decisions*, KindEthics.com (Jan. 30, 2009), <http://kindethics.com/tag/dnr/> (“First, stop asking, ‘What do you want us to do?’ And instead ask, ‘What would (the patient’s name) want us to [do]?’ . . . Secondly, you need to educate the family about their role as the decision maker . . . .”); Meth, *supra* note 106, at 2076 (recommending “[e]ducation of SDMs’ legal obligations”); Rowland, *supra* note 233, at 352 (recommending that providers “remind family members or appointed guardians that it is important to choose a course of therapy as the patient would choose for herself”). Cf. GENERAL MED. COUNCIL, *TREATMENT AND CARE TOWARDS THE END OF LIFE: GOOD PRACTICE IN DECISION MAKING* 21 (2010), available at [http://www.gmc-uk.org/Treatment\\_and\\_care\\_towards\\_the\\_end\\_of\\_life\\_0510\\_32609298.pdf\\_33387641.pdf](http://www.gmc-uk.org/Treatment_and_care_towards_the_end_of_life_0510_32609298.pdf_33387641.pdf) (making clear their role is just to advise on patient wishes, views, beliefs).

249. See Latifat Apatira et al., *Hope, Truth, and Preparing for Death: Perspectives of Surrogate Decision Makers*, 149 ANNALS INTERNAL MED. 861, 867 (2008).

250. AMA CODE OF ETHICS, *supra* note 131, § 8.081. Many cases will go undetected. “[M]edical professionals cannot guard against improper motives . . . because they are neither suited by training nor situation to discover such impropriety.” *In re Hamlin*, 689 P.2d 1372, 1381 (Wash. 1984) (Rosellini, J., dissenting). I analyze surrogate selection as a dispute resolution option for those cases in which providers do know or suspect the surrogate is unfaithful.

251. Mark D. Siegel, *End-of-Life Decision Making in the ICU*, 30 CLINICS CHEST MED. 181, 186 (2009).

Therefore, it will often be best to delay treatment decisions while the surrogate comes to terms with the patient's illness.<sup>252</sup>

#### IV. JUDICIAL REPLACEMENT OF UNFAITHFUL SURROGATES

For the small but significant subset of cases in which intramural and informal dispute resolution mechanisms fail, surrogate replacement may be an option. Indeed, it may be a legal obligation. So, why is it so underutilized?<sup>253</sup>

The main obstacle to wider acceptance of surrogate selection has not been doubt of its appropriateness, but rather of its efficacy.<sup>254</sup> The standard operating procedure in most institutions seems to be "accede to the surrogate's demands for treatment if the surrogate cannot be convinced to accept the physician's recommendation to forgo it."<sup>255</sup>

In one recent study, seventeen percent of physicians responded that "[i]f a family member or health care surrogate is making health care decisions that clearly go against the wishes stated in the patient's living will," they

252. Alexia M. Torke, *The Physician-Surrogate Relationship*, 167 ARCHIVES INTERNAL MED. 1117, 1120 (2007). Of course, delaying too long will undermine the patient's autonomy and/or best interests.

253. Some providers recognize it as an option. See, e.g., Posting of Tayyab Ali to New Eng. J. Med., <http://www.nejm.org/clinical-decisions/20090129/default.aspx?View=All#commentbox> (Feb. 02, 2009) (last visited Aug. 11, 2010) ("I wish we had a committee . . . who can make binding judgments in these situations to override unrealistic choices by surrogate decision makers."); postings of Anthony Gagliardi, Ramón Trevino-Frutos, Stephen Workman, Donald Winston, Anne-Marie Hill, Luciano Corrêa da Silva Müller, George Schroeder, Giovanni Codacci-Pisanelli, Tom Mayo to New England J. Med., <http://www.nejm.org/clinical-decisions/20090129/default.aspx?View=All#commentbox> (2009) (last visited Aug. 11, 2010); Jennifer Frank, *Refusal: Deciding to Pull the Plug*, 23 J. AM. BOARD FAM. MED. 671, 673 (2010) ("I disregard what the families request if they go against what the patient would want . . .").

254. See Meth, *supra* note 106, at 2075 ("[L]egal recourse is avoided as health-care providers perceive that the legal forum fails to provide informed and timely resolution . . . . [P]hysicians may 'err on the side of caution' by continuing life-sustaining interventions, even if treatment is believed to be against the patients' wishes."); Thaddeus Mason Pope, *Involuntary Passive Euthanasia in U.S. Courts: Reassessing the Judicial Treatment of Medical Futility Cases*, 9 MARQ. ELDER'S ADVISOR 229, 267 (2008) ("[F]ear of legal liability should not have the impact on provider decision-making that it has had.").

255. Meisel & Jennings, *supra* note 136, at 76. In the *New England Journal of Medicine* poll, many respondents admitted that they would cave in to the unfaithful son's demands because of legal concerns. See postings of Adolfo Anchondo, Aarti Jerath, John Lace, James Holmlund, Marc Hirsch, B Douglas, Alvin Fuse, Moises Malowany, Albert Fuchs, Casey Hager, David Mehr, George Schroeder, Russell Buhr, Audrey Peterson to New England J. Med., <http://www.nejm.org/clinical-decisions/20090129/default.aspx?View=All#commentbox> (2009). See also Kritek 2009, *supra* note 1, at e16 (reporting that many respondents "believed they were limited, by legal concerns....").



would follow the family's wishes and not the living will.<sup>256</sup> It is, in short, often easier to accede and provide treatment. "In such cases, patients are often quite near death anyway, and they die in a relatively short time while treatment continues to be administered."<sup>257</sup>

But the available legal precedent suggests that this reluctance to seek judicial surrogate replacement is unwarranted.<sup>258</sup> Admittedly, in early futility cases, courts were generally unwilling to negate a surrogate's right to make health care decisions on behalf of a patient.<sup>259</sup> But in more recent cases, providers have repeatedly successfully replaced surrogates who demanded LSMT that providers deemed inappropriate.<sup>260</sup>

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256. Dan M. Westphal & Stefanie Andrea McKee, *End-of-Life Decision Making in the Intensive Care Unit: Physician and Nurse Perspectives*, 24 AM. J. MED. QUALITY 222, 225 tbl. 3 (2009) (reporting that seventy-two percent of physicians but ninety-one percent of nurses would follow the living will). See also *id.* at 226 (reporting that the "main reason" physicians would follow family wishes that "clearly go against the . . . patient's living will" was "fear of litigation"); BERNAT, *supra* note 174, at 84 ("A patient or family's verbal or veiled threat to pursue legal action often is sufficient to win whatever demand either makes on the physician."); Berger et al., *supra* note 147, at 49 ("Despite substantial evidence of surrogate inaccuracy . . . many physicians do not require surrogates to adhere to patients' known wishes, and physicians often treat incapacitated patients contrary to expressed preferences."); Charlie Corke & Jill Mann, *Effect of a Supplement Clarifying Patients' Intentions on Doctors' Willingness to Follow the Wishes of an Agent with Medical Enduring Power of Attorney*, 11 CRITICAL CARE & RESUSCITATION 215, 217 (2009) (finding only forty percent of surveyed physicians believed that they had a "duty to overrule" a surrogate's wrong decision); Jennifer Murphy et al., *Withdrawal of Care in a Potentially Curable Patient*, 147 SURGERY 441, 443 (2010) ("[T]here might be legal consequences of failing to comply with the requests of the DPA.").

257. Meisel & Jennings, *supra* note 136, at 73.

258. BERNAT, *supra* note 174, at 83 ("If physicians, in their usual practice of following the law, find that doing so in a particular instance clearly produces more harm than good to a patient or others, if possible, they should contact a hospital attorney and seek a court order legally authorizing them to make an exception to the law."); *id.* at 84 (arguing that rather than "capitulating to the demand," physicians should "courageously stand by their medical judgments"); Lo et al., *supra* note 221, at 1492 (arguing that physicians "should accept a degree of legal uncertainty in order to do what is ethically and clinically appropriate").

259. See Cantor, *supra* note 172, at 886 ("[P]roviders can seek a judicial declaration that the surrogate is acting improperly; but the judicial route is currently likely to fail . . ."); Lee, *supra* note 8, at 487; RIGHT TO DIE, *supra* note 4, § 3.16[b][3] (observing that few cases have addressed the issue of the appropriate person to serve as judicially appointed guardian).

260. It is rarely necessary for the replacement of surrogates to be made by a court. Physicians normally themselves have the authority to determine whom they will recognize as a valid surrogate. Still, most physicians want the legal comfort of a judicial declaration. In any case, it is important to review the appellate precedent because this cases a "shadow" on how surrogate selection will occur in the wards. Cf. Pope & Waldman, *supra* note 11, at 149 (discussing the application of mediation in end-of-life care).

### A. Early U.S. Cases: 1990-1995

*In re Wanglie* is one of the earliest and most widely discussed medical futility cases.<sup>261</sup> Helga Wanglie was an eighty-six year old woman who was in a persistent vegetative state and dependent on a ventilator as a result of cardio-respiratory arrest.<sup>262</sup> Her providers determined that she could never appreciate any benefit from continued LSMT, so they advised her husband, Oliver, to remove the ventilator.<sup>263</sup> However, Oliver would not consent to stopping LSMT.<sup>264</sup>

The providers petitioned the local probate court to appoint a professional conservator to make health care decisions for Helga.<sup>265</sup> The hospital-nominated conservator presumably would accede to the providers' recommendation to stop LSMT, although at the time of the appointment he was not familiar with the facts of the case.<sup>266</sup> Despite the provider's efforts, the probate court denied the petition and instead appointed Oliver as conservator.<sup>267</sup> The court noted that Oliver was Helga's husband of fifty-three years.<sup>268</sup> Moreover, his decision to continue LSMT did not constitute grounds to remove his decision-making authority.<sup>269</sup> The court could not conclude that Oliver's decision to continue LSMT was inconsistent with Helga's preferences or best interests.<sup>270</sup>

While *Wanglie* is certainly the most famous case from the early 1990s in which a court rejected a provider's attempt at "surrogate selection," it is not the only case.<sup>271</sup> In *Nguyen v. Sacred Heart Medical Center*, a Washington court rejected a provider's argument that a child's parents serving as surrogate decision-makers should be replaced because their decision to continue LSMT constituted child abuse.<sup>272</sup> Similarly, a District of Columbia

261. *In re Wanglie*, *supra* note 24, at 369.

262. *Id.* at 374-75.

263. *Id.* at 371.

264. *Id.*

265. *Id.* at 371, 376.

266. *In Re Wanglie*, *supra* note 24, at 371.

267. *Id.* at 372, 377.

268. *Id.* at 376.

269. *Id.* at 371.

270. *Id.* at 377.

271. See *In re Doe*, 418 S.E.2d 3, 7 (Ga. 1992) (holding that providers could not withdraw LSMT from a child with only the mother's consent where the child's father was available). Professor Annas suggests *Doe* is not a futility case, but instead a dispute about who is the authorized decision-maker. George J. Annas, *The Case of Baby K*, 331 NEW ENG. J. MED. 1383, 1385 (1994). This is belied by the course of the litigation, which demonstrated that the hospital was hardly agnostic as to which parent had authority. It argued that "continued aggressive treatment . . . constituted medical abuse." *In re Doe*, 418 S.E.2d at 4.

272. See *Nguyen v. Sacred Heart Medical Center*, 987 P.2d 634, 638 (Wash. Ct. App. 1999); John Altomare & Mark Bolde, *Nguyen v. Sacred Heart Medical Center*, 11 ISSUES L. &

court refused to replace a mother as surrogate decision-maker for her critically ill two-month-old baby simply because she requested continued LSMT.<sup>273</sup>

Some commentators cite *Wanglie* and other cases from the early 1990s to conclude that the strategy of having an alternative decision maker appointed by the court is "rarely successful."<sup>274</sup> But it appears that these early decisions have little relevance today.<sup>275</sup> Emboldened by empirical evidence attacking the accuracy of surrogate decisions,<sup>276</sup> providers have been increasingly able to establish that surrogates refusing to follow recommendations to stop LSMT are not acting in patients' preferences or best interests.<sup>277</sup>

#### B. Later U.S. Cases: 1995-2010

By the mid-1990s, judicial hostility to surrogate shopping began to wane. Courts began regularly replacing surrogates in three types of cases. First, they replaced surrogates who made decisions inconsistent with instructions in the patient's advance directive. Second, courts replaced surrogates who requested treatment inconsistent with the patient's preferences or best interests. Third, courts replaced surrogates who suffered from a material conflict of interest.

##### 1. Judicial Replacement of Surrogates Making Decisions Inconsistent with the Patient's Advance Directive

Advance directives are not always clear, and providers should comply with surrogate decisions so long as the surrogate interprets the advance

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MED. 199, 200 (1995) (noting that while the hospital attempted to characterize continued treatment as "cruel and inhumane," the court held that the argument had no merit). This abuse argument had also failed in earlier cases. See, e.g., *In re Baby K*, 832 F.Supp. 1022, 1031 (E.D.Va. 1993) (ruling that the mother's decision to continue treatment was not "so unreasonably harmful as to constitute child abuse or neglect").

273. Benjamin Weiser, *A Question of Letting Go: Child's Trauma Drives Doctors to Reexamine Ethical Role*, WASH. POST, July 14, 1991, at A18 (detailing the case of baby Rena).

274. Burns & Truog, *supra* note 20, at 1989.

275. While the answers to the legal questions asked in *Wanglie* and *Nguyen* disfavored providers, these are not the only questions relevant in medical futility cases. Cf. RIGHT TO DIE, *supra* note 4, § 13.03[A]. Providers can also seek *ex ante* permission or *ex post* forgiveness for unilaterally refusing a surrogate's request, declaratory relief, or providers can proceed to withdraw LSMT and defend any subsequent damages case. See generally Pope 2007, *supra* note 19, at 42-78; Pope 2009, *supra* note 16, at 276-279.

276. See *supra* notes 178 to 181 and accompanying text.

277. See *infra* Part B.

directive in good faith in light of available information and circumstances.<sup>278</sup> But when the surrogate's interpretation becomes seriously strained or obviously wrong, the surrogate has exceeded the scope of her authority. In these situations, courts have not hesitated to replace such surrogates.

Perhaps the most significant of these decisions is *In re Livadas*.<sup>279</sup> 97-year-old Dorothy Livadas was in a persistent vegetative state and dependent on a PEG tube and a ventilator.<sup>280</sup> Her daughter and healthcare agent, lanthe, wanted health care providers to continue this treatment because her mother was "not done."<sup>281</sup> But health care providers did not think that was the right decision for Livadas.<sup>282</sup> In April 2008, a New York trial court appointed Catholic Family Center as Livadas' guardian, a decision later affirmed by the appellate division.<sup>283</sup> The court replaced lanthe as surrogate decision maker both because her demands for aggressive treatment contradicted instructions in her mother's advance directive and because she "fail[ed] to appreciate her mother's true medical condition and lack[ed] the objectivity and insight to make necessary decisions."<sup>284</sup>

The California Court of Appeal similarly endorsed surrogate selection in *Cardoza v. USC University Hospital*.<sup>285</sup> While the court did not replace a surrogate, it strongly indicated that there are clear limits to the scope of a surrogate's authority.<sup>286</sup> Healthcare providers complied with decisions of an

278. See *In re Drabick*, 200 Cal.App.3d 185, 200 (Cal. Ct. App. 1988) (holding the court should confine its involvement to ensuring that surrogate has made a "good faith" decision relying on medical advice).

279. *In re Livadas*, No. 08/037030 (N.Y. Apr. 28, 2008).

280. *Id.* at 2. See also Justina Wang & Gary Craig, *In the Gray Area Between Life, Death, DEMOCRAT & CHRON.*, Aug. 11, 2008, at 1A.

281. *In re Livadas*, No. 08/037030, at 2. See also Wang & Craig, *supra* note 280, at 1A.

282. *In re Livadas*, No. 08/037030, at 4-6. See also Wang & Craig, *supra* note 280, at 8A; Gary Craig & Justina Wang, *Removal of Life Support Allowed*, DEMOCRAT & CHRON., Aug. 21, 2008, at 1A.

283. *In re Livadas*, No. 08/037030, at 14, 16-17. See also Wang & Craig, *supra* note 280, at 8A; Craig & Wang, *supra* note 282, at 6A.

284. *In re Livadas*, No. 08/037030, at 14-15. A few weeks after its appointment, CFC, the new guardian, authorized the removal of Livadas' life support based on the numerous legal documents, including a 2005 living will, Livadas had signed. *Id.* at 3. Observe that while Livadas' living will clearly applied to her then-present circumstances, the result was still premised on the assumption that Livadas' living will accurately represented her preferences. *Id.* lanthe argued that since Livadas signed many legal papers the same day she signed her living will, it is unlikely that she put much thought into it. *Id.* at 8-9. Indeed, it is likely that many living wills (instructional advance directives) accurately reflect the preferences of declarants. Still, the presumption is that they do, and lanthe could not bear the heavy burden of rebutting this presumption.

285. *Cardoza v. USC Univ. Hosp.*, No. B195092, 2008 WL 3413312 (Cal. Ct. App. 2008).

286. *Id.* at \*5.

appointed health care agent, a son of the patient, to continue aggressive interventions for his mother.<sup>287</sup> But the agent's sister (and patient's daughter) brought a lawsuit alleging that providers failed to comply with her mother's advance directive.<sup>288</sup> Since the surrogate had no authority to contravene instructions and preferences memorialized in the advance directive, the hospital could not have complied with the surrogate's decisions "in good faith."<sup>289</sup> Therefore, the court held that the hospital was not entitled to immunity.<sup>290</sup> The hospital, the court implied, should have replaced the surrogate.<sup>291</sup>

## 2. Judicial Replacement of Surrogates Making Decisions Inconsistent with the Patient's Preferences or Best Interests

Replacing a surrogate who is making decisions contrary to a patient's advance directive may be an easy case.<sup>292</sup> But the courts have not stopped there. They have been replacing surrogates in situations where the only ground for disqualification was the fact that the surrogate demanded LSMT for the patient contrary to provider recommendations.<sup>293</sup> Courts are prepared to override even well-intentioned surrogates whose demands for continued LSMT cause a patient unwarranted or extreme suffering.<sup>294</sup>

For example, in *In re Mason*, the Massachusetts General Hospital successfully moved the local probate court to "override" a health care agent's refusal to consent to a do not resuscitate ("DNR") order.<sup>295</sup> In granting the hospital's petition, the court explained that since the agent was

287. *Id.* at \*1.

288. *Id.*

289. *Id.* at \*5.

290. *Id.*

291. *Cardoza*, WL 3413312 at \*5.

292. *Cf. Cantor*, *supra* note 172, at 887 n.16 (observing that the easier case is where the "patient had, while previously competent, issued instructions rejecting life support in the circumstances now at hand").

293. See John Zick, *Man's Life in Court's Hands*, CORNING LEADER, June 22, 2009, <http://www.the-leader.com/news/x998779933/Man-s-life-in-court-s-hands>; see also *Kisner v. W.V. Univ. Hosp.*, No. 10-C-190 (Monogalia Cty., WV Cir. Ct., Mar. 25, 2010) (Complaint) (alleging that the hospital "intends to remove the Plaintiff as surrogate" because of evidence that the patient "would refuse the level of medical intervention and treatment decided by the Plaintiff").

294. *Cf. In re Guardianship of Myers*, 610 N.E.2d 663, 664 (Ohio Misc. 1993) (appointing guardian other than parents of permanently comatose minor where one parent refused to consent to stopping LSMT).

295. *In re Guardianship of Mason*, 669 N.E.2d 1081, 1082 (Mass. App. Ct. 1996).

"in denial" about his mother's deterioration and distrustful of her providers, he had not given "full consideration of acceptable medical alternatives."<sup>296</sup>

Similarly, in the case of Gary Harvey, the court replaced the patient's wife as surrogate because she failed to follow medical advice.<sup>297</sup> In January 2006, Gary Harvey fell down his basement stairs, leaving him in a persistent vegetative state.<sup>298</sup> Providers soon determined that Harvey was suffering and had little to no chance of recovery.<sup>299</sup> While his wife, Sara, was initially appointed guardian, she "showed a pattern of dangerous behavior."<sup>300</sup> So, in February 2007, a court replaced Sara because she "failed to use good judgment and follow medical advice."<sup>301</sup> The new guardian, Chemung County, New York Department of Social Services, following the recommendation of the hospital ethics committee, asked the trial court to authorize both the issuance of a DNR order and the removal of the Harvey's artificial nutrition and hydration.<sup>302</sup>

In a case referred to as *Baby Terry*, the court replaced the parents of two-month-old Terry Achtabowski Jr. with a guardian.<sup>303</sup> Baby Terry was born premature at twenty-three weeks gestation, was dependent on a ventilator, and had a host of serious medical problems that made his prognosis very bleak.<sup>304</sup> Since continued treatment was painful and offered virtually no prospect for recovery, the Genesee County, Michigan Department of Social Services alleged that Baby Terry's parents were neglectful in requesting continued treatment.<sup>305</sup> The Michigan Probate Court did not find the parents neglectful, but it did determine that they were

296. *Id.* at 1085. One might say that the surrogate lacks capacity, just as the patient herself lacked capacity, to understand and make the healthcare decisions at hand.

297. See Zick, *supra* note 293.

298. *Id.*

299. *Id.*

300. Scott Cook & Ted Fioraliso, *Gary Harvey's Daughter Speaks Out*, WENY.COM (Dec. 16, 2009), <http://www.weny.com/news-local.asp?article3864=9149983>.

301. Zick, *supra* note 293 ("Sara Harvey says her husband is a fighter who would not want to give up." "They think that I'm in denial."). See also Ray Finger, *Wife Accused of Abuse Wants Guardianship of Husband*, STAR GAZETTE, Sept. 18, 2009, at 6A ("In his February 2007 decision that denied Sara Harvey guardianship, state Supreme Court Judge Robert Mulvey said she had abused Gary Harvey and failed to follow medical advice.").

302. See Zick, *supra* note 293. The county guardian later withdrew its request to remove Harvey's feeding tube. John Zick, *Comatose Man's Feeding Tube Won't be Removed*, CORNING LEADER, July 28, 2009, <http://www.the-leader.com/news/x639778616/Comatose-mans-feeding-tube-won-t-be-removed>.

303. Bopp, Jr. & Coleson, *supra* note 97, at 825-27 (discussing the case of Baby Terry, *In re Achtabowski*, No. G93142173GD (Mich. Probate Ct. July 30, 1993)); *Baby Dies, Was Focus of Battle*, ORLANDO SENTINEL, Aug. 13, 1993, at A10 (Parents could not block court-appointed guardian.).

304. Bopp, Jr. & Coleson, *supra* note 97, at 825.

305. *Id.*

"incompetent" to decide what was best for their son.<sup>306</sup> The court reasoned that the parents lacked the requisite capacity to make medical decisions for their son because their demands for continued LSMT evidenced that they were emotionally unable to appreciate the circumstances.<sup>307</sup>

In *In re Howe*,<sup>308</sup> the Massachusetts Probate Court initially seemed to return to the early 1990s hostile approach to surrogate selection. The court ruled that when a surrogate decision-maker insisted on continued LSMT for her mother, "the evidence is insufficient to warrant court usurpation of [a daughter's] role as her mother's health care agent."<sup>309</sup> But as the patient's condition deteriorated further, the daughter's decision to continue LSMT increasingly diverged from the hospital's assessment of the patient's preferences and best interests.<sup>310</sup>

Several months later, the court suggested that the surrogate's own personal issues were "impacting her decisions" and urged the daughter to "refocus her assessment."<sup>311</sup> A year later, the hospital again planned to remove LSMT, and the court denied the daughter's request for a temporary restraining order (TRO).<sup>312</sup> The daughter soon agreed to withdraw LSMT because she thought the court would rule against her.<sup>313</sup>

Finally, in *Bernstein v. Superior Court*,<sup>314</sup> the dispute was between two sons of a 79-year-old Alzheimer's patient.<sup>315</sup> One brother, Scott, had been the conservator.<sup>316</sup> But Scott had been demanding very aggressive care that offered the father no benefit, only significant suffering.<sup>317</sup> While healthcare providers were not a party to the dispute, they all thought that the treatments were "inappropriate" and "futile."<sup>318</sup> On the basis of the providers'

306. *Id.* at 826.

307. *Id.* at 826, 832. Cf. Linda C. Fentiman, *Health Care Access for Children with Disabilities*, 19 PACE L. REV. 245, 261-63 (1999) (describing case as a "troubling example of judicial and physician usurpation of parental authority to make decisions about the medical treatment of their children").

308. *In re Howe*, No. 03 P 1255, 2004 WL 1446057 (Mass. Prob. & Fam. Ct. Mar. 22, 2004).

309. *Id.* at \*21.

310. *Id.* at \*20.

311. *Id.* at \*20, \*21.

312. See Liz Kowalczyk, *Plan to Take Woman Off Life Support Is Halted*, BOS. GLOBE, Feb. 23, 2005, at B1.

313. *Daughter Explains Agreement to End Care*, BOS. GLOBE, Mar. 23, 2005, at B2.

314. *Bernstein v. Sup. Ct. Ventura Cty.*, No. B212067, 2009 WL 224942 (Cal. Ct. App. Feb. 2, 2009).

315. *Id.* at \*1.

316. *Id.*

317. *Id.* at \*2.

318. *Id.* at \*4-5.

testimony, the other brother, Ilya, successfully replaced Scott as conservator.<sup>319</sup>

### 3. Judicial Replacement of Surrogates Suffering a Material Conflict of Interest

While courts replace surrogates requesting treatment contrary to patient instructions, preferences, and best interests, perhaps the easiest surrogate for courts to replace is one with a material conflict of interest. In the prescient 1997 film *Critical Care*, the daughter of a terminally ill man demanded that healthcare providers sustain her father.<sup>320</sup> She claimed that this is what her father would have wanted.<sup>321</sup> In fact, if the father lived for three more weeks, the daughter would inherit \$10 million.<sup>322</sup> If the father died sooner, another daughter from another marriage would inherit the money.<sup>323</sup> Clearly, surrogates basing their treatment decisions on such selfish, non-patient-oriented reasons should be replaced.<sup>324</sup> And they are.

319. *Id.* at \*10-11, 14.

320. *CRITICAL CARE* (Live Entertainment 1997). Such a motive obtained more generally in 2009, because the inheritance tax was lifted for deaths in 2010. Laura Saunders, *Rich Cling to Life to Beat Tax Man*, WALL ST. J., Dec. 30, 2009, at A1, available at <http://online.wsj.com/article/SB126213588339309657.html>. One New York lawyer explained, in late December 2009, "I have two clients on life support, and the families are struggling with whether to continue heroic measures for a few more days." *Id.* Of course, surrogates making such decisions on such a basis is not problematic if that is what the patient wanted. "[S]ome clients are putting provisions into their health-care proxies allowing whoever makes end-of-life medical decisions to consider changes in estate-tax law." *Id.*

321. *CRITICAL CARE*, *supra* note 320.

322. *Id.*

323. *Id.* See also Maura Possley, *Family Members Upset with Care of Elderly Aunt*, SOUTHTOWN STAR, Mar. 26, 2010 (describing a case eerily similar to that depicted in *CRITICAL CARE*).

324. See, e.g., *Files v. State*, 826 So. 2d 906 (Ala. Crim. App. 2001) (affirming conviction for criminally negligent homicide of conservator, sole heir of her aunt's estate, who diluted and discontinued her aunt's feeding tube); Lois Shepherd, *Terri Schiavo: Unsettling the Settled*, 37 LOY. U. CHI. L. REV. 297, 304 (2006) (observing that the Schindlers claimed that Michael Schiavo was motivated by money to remove Terri's feeding tube, but that the trial court found no basis for those charges); Jenette Sturges, *Public Guardian Often Can Help the Helpless*, NAPERVILLE SUN, July 26, 2010 (reporting the case of Mary Rauschenberger, in which the county guardian obtained a DNR order on the physician's recommendation, despite the objections of family members who were living off the patient's trust). Not only do such conflicted decisions violate general fiduciary obligations but they may also violate specific prohibitions. See, e.g., ALA. CODE § 22-8A-11(c) (LexisNexis 2006) ("The decision to provide, withdraw, or withhold life-sustaining treatment . . . by the surrogate shall be made . . . without consideration of the financial benefit or burden which will accrue to the surrogate or the health care provider as a result of the decision.").



In *In re Rochester General Hospital*,<sup>325</sup> Mr. Levin was admitted to the hospital for "certain medical problems experienced while a patient in a nursing home."<sup>326</sup> Mr. Levin's adult son had been granted a health care proxy and appointed surrogate decision maker under a power of attorney.<sup>327</sup> But the son "refused to cooperate in obtaining Medicaid reimbursement to cover the hospital expenses," apparently because he had wrongfully withheld his father's property.<sup>328</sup> The hospital commenced a special proceeding for the appointment of guardian.<sup>329</sup> The court granted the petition, explaining that it "entertain[ed] serious doubts as to [the son's] ability to make future decisions pursuant to the health care proxy."<sup>330</sup>

Not all conflicts are financial in nature.<sup>331</sup> For example, in *In re Martin*,<sup>332</sup> the mother of a patient challenged the appropriateness of the patient's wife as surrogate.<sup>333</sup> The Michigan Court of Appeals held that it was error for the trial court to have not considered evidence of the possible bias, prejudice, conflict of interest, or improper motive.<sup>334</sup> Such evidence would indicate that the wife was not a suitable surrogate.<sup>335</sup>

325. *In re Rochester Gen. Hosp.*, 601 N.Y.S.2d 375 (N.Y. 1993).

326. *Id.* at 377.

327. *Id.*

328. *Id.* at 377, 379.

329. *Id.* at 377.

330. *Id.* at 379. Financial conflicts of interest often lead to breaches of fiduciary duty not only in the healthcare context but also in the context of the ward's estate. See, e.g., *Grahl v. Davis*, 971 S.W.2d 373, 380 (Tenn. 1998) (holding that the conservator breached her fiduciary duties for allowing redemption of certificates without court approval and for dealing with the property to attain personal benefit); *Bryan v. Holzer*, 589 So. 2d 648, 660 (Miss. 1991) (holding that the conservator using ward's funds for his own use violated fiduciary duties); *In re Guardianship of Lawrence*, 563 So. 2d 195, 197 (Fla. Dist. Ct. App. 1990) (holding that the guardian violated fiduciary duties by taking compensation and mismanaging funds). In October 2009, a Manhattan jury convicted the son of philanthropist Brooke Astor, on charges that he defrauded his mother and stole tens of millions of dollars from her as she suffered from Alzheimer's. John Eligon, *Mrs. Astor's Son Guilty of Taking Tens of Millions*, N.Y. TIMES, Oct. 9, 2009, at A1, available at <http://www.nytimes.com/2009/10/09/nyregion/09astor.html>; Joseph A. Rosenberg, *Regrettably Unfair: Brook Astor and the Other Elderly in New York*, 30 PACE L. REV. 1004 (2010).

331. See, e.g., RIGHT TO DIE, *supra* note 4, at § 3.24[C] (Conflicts can be emotional in nature as well.); STANLEY A. TERMAN, PEACEFUL TRANSITIONS: AN IRONCLAD STRATEGY TO DIE HOW AND WHEN YOU WANT 66-68 (2009).

332. *In re Martin*, 517 N.W.2d 749 (Mich. Ct. App. 1994), *rev'd on other grounds*, 538 N.W.2d 399 (Mich. 1995).

333. *Id.* at 750.

334. *Id.* at 753-54.

335. *Id.* at 754.

More starkly, in June 2009, Pedro Rosabal killed his two children, then turned the gun on himself and ended up on life support.<sup>336</sup> Legal and ethical experts agreed that it would be inappropriate for decisions regarding Rosabal's treatment to end up in the hands of his wife (the dead children's mother).<sup>337</sup>

In a recent Arizona case, the patient's wife was removed as surrogate because of demonstrated animosity and enmity.<sup>338</sup> In 2007, Jesse Ramirez and his then-wife, Rebecca were involved in a terrible rollover car crash.<sup>339</sup> Jesse suffered a broken neck, fractured skull, punctured lung, broken ribs, and fractured face.<sup>340</sup> He was comatose in a minimally conscious state.<sup>341</sup> Just nine days later, even before Jesse's prognosis was certain, Rebecca directed the removal of his feeding tube.<sup>342</sup> But Jesse's siblings and parents objected.<sup>343</sup> They alleged that Rebecca had exceeded the scope of her authority.<sup>344</sup> Not only was there was marital discord but the couple had also been in a heated argument right at the time of the accident.<sup>345</sup> Based on this evidence, the Maricopa County Superior Court appointed an independent guardian.<sup>346</sup> Jesse's nutrition and hydration was resumed, and he was later discharged.<sup>347</sup>

Sadly, one type of conflicted surrogate whom courts regularly replace is the parent whose very own physical abuse caused a child's dependence on LSMT.<sup>348</sup> For example, in the case of Michael Arzuaga-Guevara, life

336. Cindy George & Paige Hewitt, *Kids' Deaths Put Hospital in Ethical Quandary*, HOUS. CHRON., June 18, 2009, <http://www.chron.com/disp/story.mpl/hotstories/6487574.html>.

337. *Id.*

338. Gary Grado, *Judge Orders Life Support for Hospice Patient*, E. VALLEY TRIB., June 15, 2007, at A1.

339. *Id.*

340. *Id.*

341. *Id.*

342. *Id.*

343. Grado, *supra* note 338.

344. *Id.* Gary Grado, *Crash Survivor's Case Spurs New State Law for Incapacitated People*, E. VALLEY TRIB., July 19, 2009, at A5.

345. Grado *supra* note 338; Grado *supra* note 344.

346. Grado, *supra* note 338.

347. Grado, *supra* note 344. See also Dennis Wagner, *Man Wakes After Order to End Life Support*, USA TODAY, June 27, 2007, at 3A, available at [http://www.usatoday.com/news/nation/2007-06-26-comatose\\_N.htm](http://www.usatoday.com/news/nation/2007-06-26-comatose_N.htm) (stating Ramirez awoke from his coma eighteen days after his wife instructed his physicians to remove life support and was able to sit up and communicate with visitors). A similar issue arose when *Different Strokes* actor Gary Coleman's ex-wife Shannon Price directed the removal of his life support. Nancy Dillon, *Gary Coleman's Wife on Why She Yanked His Life Support: "He Wouldn't Have Made It Anyway,"* N.Y. DAILY NEWS, June 3, 2010.

348. See, e.g., *Hernandez v. Abel*, No. 2:06-CV-02582-MBS (D.S.C. Feb. 4, 2008) (granting summary judgment to defendants and rejecting arguments of father convicted of

support was withdrawn from a critically injured infant, over the objections of his father who was in jail on assault and related charges in connection with Michael's injuries.<sup>349</sup> Another case involved a mother who abused her two-year-old baby.<sup>350</sup> Providers recommended stopping LSMT, but the baby's father refused because he was concerned about his wife's criminal liability.<sup>351</sup> The hospital prepared to ask a court to appoint a guardian because the father was looking out for his wife's interests, not the interests of the child patient.<sup>352</sup>

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child abuse that he was wrongly excluded from the removal decision); J. M. Appel, *Mixed Motives, Mixed Outcomes When Accused Parents Won't Agree to Withdraw Care*, 35 J. MED. ETHICS 635, 635 (2009) (reviewing cases in which "accused parents . . . argued against disconnecting" but "in each instance, the courts ruled against the accused parent"); Julie Akiko Gladsjo et al., *Termination of Life Support After Severe Child Abuse: The Role of a Guardian ad Litem*, 113 PEDIATRICS e141, e141-42 (2004) (explaining the American Academy for Pediatrics' recommendation that in severe child abuse cases the accused parents may have a conflict of interest due to legal liability and it may be necessary for a court to appoint a guardian ad litem for medical decision-making); Vanessa Miller, *Boulder County Officials Discuss Injured Infant's Future*, COLORADODAILY.COM, July 29, 2009, [http://www.coloradodaily.com/ci\\_13129231?IADID=Search-www.coloradodaily.com-www.coloradodaily.com#a\\_xzz0ga8aD0xo](http://www.coloradodaily.com/ci_13129231?IADID=Search-www.coloradodaily.com-www.coloradodaily.com#a_xzz0ga8aD0xo) ("In cases where parents are suspected of being responsible for their child's injuries . . . they 'can't participate in the decision of whether to remove a child from life support.'"). Surrogates are also replaced in the opposite situation, where they refuse to consent to treatment with life-saving benefits and minimal risks. See, e.g., Thaddeus Mason Pope, *Legal Update*, 20 J. CLINICAL ETHICS 287, 288 (2009) (reviewing recent cases).

349. *In re Michael Arzuaga-Guevara*, 794 A.2d 579, 581 (Del. 2001). See also *In re Truselo*, 846 A.2d 256, 264, 274 (Del. Fam. Ct. 2000) (determining that for child severely shaken and dropped that his "best interests [was] to forego the use of heroic medical efforts to resuscitate him, that the ventilator should be removed," and that he should receive comfort measures only).

350. Steve Twedt, *Should Comatose Baby Live? Hospital, Dad Differ*, PITTSBURGH PRESS, June 3, 1990, at A1.

351. *Id.*

352. *Id.* The father then acceded to the hospital's recommendation to withdraw LSMT. J. Kenneth Evans, *Boy's Death Is Homicide, Mother May Be Charged*, PITTSBURGH POST-GAZETTE, June 25, 1990, at 1; Mary Pat Flaherty, *Right-to-Die Decision Has Little Impact Here*, PITTSBURGH PRESS, June 27, 1990, at A1. Cf. *J.N. v. Sup. Ct.*, 67 Cal. Rptr. 3d 384, 391 (Cal. Ct. App. 2007) (holding that guardian of minor has the burden of bringing expert testimony to prove that the LSMT is in the minor's best interest); *D.K. v. Commonwealth*, 221 S.W.3d 382, 384 (Ky. Ct. App. 2007) (permitting a guardian to remove LSMT once parental rights were permanently terminated); *In re Matthew W.*, 903 A.2d 333, 335 (Me. 2006) (holding that a pre-termination protection order allowing DNR for minor without parental consent violated the parents' right to due process); *In re Tabatha R.*, 564 N.W.2d 598, 605 (Neb. 1997) (discussing due process rights of parents during termination of parental rights determination); *In re Stein*, 821 N.E.2d 1008, 1013 (Ohio 2004) (finding that a limited guardian did not have the authority to withdraw LSMT when parental rights had not yet been permanently terminated); *In re Smith*, 133 P.3d 924, 929-30 (Or. Ct. App. 2006) (holding

It is important to emphasize that since surrogates are usually family members, they will be personally impacted by the patient's death, for example, in terms of inheritance, pensions, and government benefits. There is usually a conflict of interest. But this alone is insufficient to disqualify the surrogate. Instead, the moving party must establish a *material* conflict of interest. Otherwise, the very concept of surrogate decision-making would be swallowed by this exception. "[T]he issue is not the existence of a conflict of interest, but its pervasiveness and its effect."<sup>353</sup>

### C. Ontario Capacity and Consent Board

In Ontario, the Consent and Capacity Board ("CCB") is a body created by the Ontario government under its Health Care Consent Act.<sup>354</sup> "When 'in-house' conflict resolution fails, CCB can mediate. If this mediation fails, CCB adjudicates . . ."<sup>355</sup> The CCB is, in short, "an independent, quasi-judicial tribunal;" a "neutral, expert board" which, in intractable treatment disputes, can make a "legal, binding decision that can only be reversed on appeal through the courts."<sup>356</sup>

Notably, the CCB is specially designed to ensure that substitute decision makers comply with the principles of substitute decision-making.<sup>357</sup> The CCB makes its own determination. If the CCB finds that the surrogate has not complied, then it directs the surrogate to consent to treatment as the CCB finds appropriate.<sup>358</sup> If the surrogate fails to do so, then the CCB passes the right to act as surrogate to the next eligible person.<sup>359</sup>

The process is uncomplicated and expeditious. In a case where the healthcare provider judges that the surrogate is being unfaithful to the patient, the provider files a "Form G" application.<sup>360</sup> This is basically a petition for the CCB to determine whether the surrogate decision maker

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that a mother was not in a position to make decisions for her minor child where she chose not to be involved in the child's health care decisions on a regular basis).

353. RIGHT TO DIE, *supra* note 4, at § 3.24[C].

354. Health Care Consent Act, 1996 S.O., ch. 2, § 70(1) (Can.), available at <http://www.canlii.org/on/laws/sta/1996c.2sch.a/20080821/whole.html> (last visited Sept. 6, 2010).

355. Mark Handelman & Bob Parke, *The Beneficial Role of a Judicial Process When "Everything" Is Too Much?*, HEALTHCARE Q., Sept. 2008, at 46, 48.

356. *Id.* at 50. See also Joaquin Zuckerberg, *End-of-Life Decisions: A View from Ontario and Beyond*, 16 EUR. J. HEALTH L. 139, 158-59 (2009) (explaining how an administrative tribunal like the CCB "may be better suited than courts" to determine whether a surrogate has complied with the decision-making obligations).

357. Health Care Consent Act § 21 (outlining the principles for substitute decision-makers in refusing consent).

358. *Id.* §§ 36(4), 36(5).

359. *Id.* §§ 36(6), 36(6.1).

360. Handelman & Parke, *supra* note 355, at 48.

complied with the principles for substitute decision-making.<sup>361</sup> The CCB sits in expert panels comprised of a lawyer, a psychiatrist, and a public member.<sup>362</sup> Due both to an interest in expeditious decision-making and to the expertise of the CCB, the Ontario Court of Justice reviews CCB decisions under a deferential “reasonableness” standard of review.<sup>363</sup>

Regularly, when providers recommend treatment that includes the withholding or withdrawal of life-sustaining medical treatment, the CCB directs reluctant surrogates to consent.<sup>364</sup> For example, in the 2009 case of *In re N*, an 85-year-old patient was in septic shock, had numerous infections, kidney failure, and widespread skin breakdown.<sup>365</sup> She was experiencing pain, was dependent on a mechanical ventilator, and had almost no ability to come off it.<sup>366</sup> For these reasons, N’s treating physician proposed withdrawing life support and beginning palliative care.<sup>367</sup> But N’s surrogate, Mr. NP, would not consent to this plan of treatment.<sup>368</sup> Therefore, the physician brought a Form G application to the CCB “to determine if that refusal was in accordance with the principles for . . . refusing consent to treatment.”<sup>369</sup>

The CCB held that the patient had expressed “no prior capable wish that pertained to the circumstances.”<sup>370</sup> Furthermore, because Mr. NP did not accept “the medical opinion of the intensivists that N was in a state where there was no hope of recovery,” the Board held that he could not “possibly consider what N would have wanted if she was aware of those expert medical opinions[.]”<sup>371</sup> Therefore, the Board had to determine not

361. Health Care Consent Act § 37.1. See *In re E*, 2009 CanLII 28625 (Ont. C.C.B.) at 5 (“The onus is always on the health practitioner . . .”).

362. CONSENT & CAPACITY BD., ANNUAL REPORT 2007/2008 5 (2008), available at <http://www.ccboard.on.ca/english/publications/documents/annualreport20072008.pdf>.

363. *Barbulov v. Cirone*, 2009 CanLII 15889 (Ont. S.C.) at 7-8 (collecting authority). In recent cases, the Ontario Superior Court of Justice has repeatedly affirmed the CCB. See, e.g., *Grover v. Butler*, 2009 CanLII 16577 (Ont. S.C.) at 13 (holding that the Board’s decision that patient’s “prior capable wish” was inapplicable was “reasonable both in fact and in law”).

364. See, e.g., *In re E*, 2009 CanLII 28625, at 37 (directing that son comply with no-CPR, no-ventilator treatment plan of his father’s physician); *Barbulov*, 2009 CanLII 15889, at 31. (affirming CCB direction that son consent to the no-CPR, no-dialysis treatment plan proposed by his father’s physician).

365. *In re N*, 2009 CanLII 42576 (Ont. C.C.B.) at 1,7.

366. *Id.* at 1, 6-8.

367. *Id.* at 1, 3.

368. *Id.*

369. *Id.* at 1.

370. *In re N*, 2009 CanLII 42576, at 12.

371. *Id.* at 13.

whether the surrogate was acting in accord with the patient's wishes, but whether the surrogate was acting in her best interests.<sup>372</sup>

The CCB held that the surrogate was not acting in the patient's best interests.<sup>373</sup> "N had less than 1% chance of being off life support. . . . She had no quality of life. She suffered from pain. Her physical condition was going to continue to deteriorate. There was no prospect that there would be any improvement in her condition."<sup>374</sup> The Board recognized that the family held out hope, but found that "the family's hope was not at all realistic."<sup>375</sup> The Board found that the surrogate was "blinded by [his] obvious love for N and could not view her situation objectively."<sup>376</sup> Accordingly, the CCB directed Mr. NP to consent to the proposed treatment plan.<sup>377</sup>

Remarkably, the CCB has reached similar results, even in cases where the surrogate's decision had some warrant in the patient's own prior directions. While such evidence would appear to be a material obstacle to surrogate selection, the CCB is able to overcome it. The Board often finds that the patient's prior expressed preferences are inapplicable either because they are insufficiently clear or because they did not sufficiently anticipate the patient's current, very different circumstances.<sup>378</sup>

#### D. *Queensland Guardianship and Administration Tribunal*

Similar to the CCB is the Queensland Guardianship and Administration Tribunal ("QGAAT").<sup>379</sup> The Tribunal has a multidisciplinary composition

372. *Id.*

373. *Id.* at 17.

374. *In re N*, 2009 CanLII 42576, at 15.

375. *Id.*

376. *Id.*

377. *Id.* The CCB gave Mr. NP approximately 48 hours to consent to treatment in accordance with its decision.

378. See, e.g., *Conway v. Jacques* 2002 CanLII 41558 (ON C.A.) at 70, 80 (The court affirmed the CCB where the surrogate refused to consent to anti-psychotic medication for the patient because the patient had refused when he had capacity years earlier. The CCB found that the patient's wish was not applicable since currently available medication was more effective and had fewer side effects than medication available when patient articulated preferences.); *In re E*, 2009 CanLII 28625 (Ont. C.C.B.) at 28 (finding that prior comments of patient "were not precise and lacked particularly," refusing any "mechanical or literal application" of prior wishes, and thus employing best interest analysis); *Id.* at 36 ("[I]t is not open to the family to propose a treatment plan. Treatment plans are proposed by physicians and must be consented to by the substitute decision maker . . . the consent . . . must be correct."); *Barbulov v. Cirone*, 2009 CanLII 15889 (Ont. S.C.) at 20 (finding power of attorney instrument had no weight since patient "had given no prior instructions about a POA; did not read the POA [and] had limited command of written English").

379. Victoria has a similar mechanism under its Guardianship and Administration Act 1986. See *Guardianship and Administration Act 1986*, §§ 42L-42M (2008) (Austl.). If a surrogate withholds consent to treatment and the provider thinks the surrogate is not making

comprised of at least a lawyer and a professional with extensive knowledge or experience of persons with impaired decision-making.<sup>380</sup> If there is a “dispute about who should act as guardian”<sup>381</sup> or “concern about the suitability of a proposed guardian” or “someone believes inappropriate decisions are being made . . . by substituted decision makers,” then the Tribunal “may appoint the Adult Guardian, an independent statutory officer, to look after the interests of an adult with impaired decision-making ability.”<sup>382</sup>

For example, in *In re AAC*, providers determined that continuing life-sustaining measures for AAC was inappropriate because AAC’s brain function had ceased due to cardiac arrest.<sup>383</sup> But AAC’s children, who were the default surrogates (“statutory health attorneys”), refused to allow the withdrawal of life sustaining measures.<sup>384</sup> So, providers requested that an Adult Guardian consent to withdrawal, on the basis that the children’s refusal to withdraw was “inconsistent with good medical practice.”<sup>385</sup> The Adult Guardian consented.<sup>386</sup> The Tribunal rejected the children’s challenge to that decision.<sup>387</sup>

## V. THE LIMITS OF SURROGATE SELECTION

Surrogate selection is a statutorily- and judicially-recognized option for resolving intractable futility disputes. But practical problems in application

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the right decision, the provider can provide the surrogate with a notice (Section 42M Notice) within three days of the refusal. *Id.* The notice advises the surrogate that they can apply to the Victorian Civil and Administrative Tribunal (VCAT) if they want to prevent the provider from proceeding. *Id.* If the surrogate does nothing, the practitioner can proceed. *Id.* If the surrogate makes an application, VCAT will decide whether the treatment can proceed. *Id.*

380. *Id.* at 21.

381. GUARDIANSHIP & ADMIN. TRIBUNAL, GUARDIANSHIP AND ADMINISTRATION TRIBUNAL: ANNUAL REPORT 2007-2008 11 (2008). This entity was later amalgamated into the Queensland Civil and Administrative Tribunal.

382. *Id.* at 17.

383. *In re AAC* [2009] QGAAT 27 at [4]. The proceeding was brought by her child to challenge the Adult Guardian’s decision. *Id.* at [7]-[8]. The Public Guardian can withdraw LSMT where continuation is “inconsistent with good medical practice.” *Id.* at [60]. See also *In re SAJ* [2007] QGAAT 62 at [1], [52] (holding that the continuation of artificial hydration to an eighty-six year old man who was a victim of multiple strokes did not constitute good medical practice); *In re HG* [2006] QGAAT 26 at [107] (holding that the continuation of artificial hydration and artificial nutrition was inconsistent with good medical practice).

384. *In re AAC*, QGAAT at [5].

385. *Id.* at [6], [60]. Good medical practice is defined in the controlling statute as “(a) the recognized [sic] medical standards, practices and procedures of the medical profession in Australia; and (b) the recognized [sic] ethical standards of the medical profession in Australia.” Guardianship and Administration Act 2000, Schedule 2, § 5B.

386. *In re AAC*, QGAAT at [7].

387. *Id.* at [60]-[62].

limit its use.<sup>388</sup> Surrogate selection cannot be successfully applied in several significant subsets of medical futility disputes.

For three reasons, it will often be difficult to demonstrate a surrogate's deviation from required decision-making standards. First, surrogates often have sufficient evidence to demonstrate congruity between their decision and the patient's preferences. For example, surrogates might establish both that the patient belongs to a certain religion and that the tenets of that religion requires continued LSMT. Second, there will often be no available advance directive and little or no evidence of patient preferences. Therefore, it will be extremely difficult or impossible to demonstrate any contradiction between a patient's autonomy and a surrogate's decision. Third, even on the best interest standard, the benefit-burden balance is often not so obviously and severely imbalanced to justify usurping the surrogate's discretion and decision-making power.

#### A. *Surrogates Often Have Evidence to Demonstrate Congruity*

Perhaps the most obvious and the most significant limit to surrogate selection as a means for resolving futility disputes is that not all surrogates demanding medically inappropriate treatment are unfaithful. Sometimes, surrogates have solid evidence that they are making the very decisions that the patient would have wanted made on her behalf. After all, one cannot replace a "good" surrogate.<sup>389</sup>

Take, for example, a recently reported case of a sixty-four year-old man found to have an incurable cancer of the esophagus.<sup>390</sup> Because of the patient's unawareness and his very poor prognosis, his providers believed that continued ICU care was inappropriate.<sup>391</sup> But the patient's surrogate insisted that he remain in the ICU, on ventilator support and on a full code

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388. In addition to the problems described below concerning the "merits" for surrogate replacement, the time and cost of the judicial process may exceed the potential benefits. On the other hand, providers can replace surrogates without court involvement. See, e.g., 20 PA. CONS. STAT. ANN. 5431(a)(3) (providing immunity for refusing to comply with a surrogate "based on a good faith belief" that the surrogate was not complying with the standards for substitute decision making).

389. For example, in only one case was the CCB's replacement of a surrogate reversed by the Ontario Superior Court of Justice. *Scardoni v. Hawryluck*, 2004 CanLII 34326 (ON S.C.) at 31. In that case, the Court found that the evidence indicated that the patient really did desire the treatment requested by her surrogate. *Id.* at 24. See also *In re Univ. Hosp. SUNY Upstate Med. Univ.*, 754 N.Y.S.2d 153 (2002) (rejecting hospital's attempt to override surrogates through reliance on the patient advance directive because surrogates established that patient had revoked the advance directive).

390. Robert D. Orr, *Continuing "Futile" ICU Support at Relative's Insistence*, 25 ETHICS & MED. 145, 145 (2009).

391. *Id.*



status.<sup>392</sup> The surrogate explained that his deep religious faith (Methodist) required him to do everything possible to preserve life, and he was counting on God to perform a miracle.<sup>393</sup> Importantly, the surrogate further explained that “that the patient was also a man of deep faith who would likewise insist on this approach.”<sup>394</sup> It is unlikely that providers can replace this surrogate.

Indeed, religion is at the bottom of most intractable futility disputes.<sup>395</sup> For example, in the widely-discussed *Golubchuk* case, physicians determined that eighty-four year-old Samuel Golubchuk had “minimal brain function and that his chances for recovery [were] slim.”<sup>396</sup> But Golubchuk’s adult children argued that taking their father off life support would be a sin under their Orthodox Jewish faith.<sup>397</sup> Here, as in many cases, it was the patient’s religion, and not just the surrogate’s religion, that compelled continued treatment. Under such circumstances, it is difficult to replace such faithful surrogates.

Surrogate selection seems inappropriate and inadequate to address this most common type of intractable futility dispute.<sup>398</sup> Furthermore, a practical reality seriously exacerbates this problem. Surrogates are a primary source of information about the patient’s preferences and values.<sup>399</sup> So no matter what the applicable evidentiary standard, surrogates could “manufacture” or at least “polish” evidence to meet that standard.<sup>400</sup> And the limitations do not stop there.

392. *Id.*

393. *Id.*

394. *Id.*

395. See Pope & Waldman, *supra* note 11, at 167.

396. Carla Tonelli, *Canada Life-Support Case Pits Religion vs. Science*, REUTERS UK, Dec. 14, 2007, <http://uk.reuters.com/article/idUKN1321757620071214> (discussing *Golubchuk v. Salvation Army Grace Gen. Hosp.*, 2008 MBQB 49 (CanLII)).

397. See *id.* at 415.

398. See Nat’l Right to Life, *Why the Need for a “Will to Live”?*, <http://www.nrlc.org/euthanasia/willtolive/Whyneedwtl.html> (last visited Sept. 6, 2010). See also Texas Right to Life, *Will to Live*, [http://www.texasrighttolife.com/lifelssues\\_euthanasia\\_will.php](http://www.texasrighttolife.com/lifelssues_euthanasia_will.php) (last visited Sept. 6, 2010) (“If you . . . do not want to be starved, dehydrated, or allowed to die simply because you have a disability, the medical community will be far more likely to respect your wishes if you sign a properly prepared Will to Live . . .”).

399. See *A.M. v. Benes*, [1999] CanLII 3807 (ON C.A.) at 10 (“The Board, though it may substitute its opinion for that of the S.D.M., must nonetheless take into account the S.D.M.’s submissions on the incapable person’s values, beliefs and non-binding wishes . . .”).

400. See Sandra H. Johnson, *Quinlan and Cruzan: Beyond the Symbols*, in *HEALTH LAW AND BIOETHICS: CASES IN CONTEXT* 53, 65-66 (2009) (stating that after the U.S. Supreme Court upheld that constitutionality of Missouri’s clear and convincing evidentiary standard, Judge Teel found that standard satisfied on remand and denied that he assisted in manufacturing evidence).

B. *Providers Often Lack Sufficient Evidence to Demonstrate Surrogate Deviation*

In many futility disputes it will be difficult for providers to demonstrate that because surrogates demand continued treatment, they are being unfaithful to patient instructions or preferences. First, since applicable instructions are rarely available, cases like *Livadas* will be rare.<sup>401</sup> It is impossible to demonstrate surrogate deviation from patient instructions, if there are no such instructions in the first place. Second, there is a dearth of not only advance directives but also of any other evidence regarding patient preferences. Without such evidence, providers cannot demonstrate surrogate deviation. Third, even when patient instructions or evidence of patient wishes is available, patients often trust their surrogates' discretion and want the surrogates to not be strictly bound by those instructions and wishes.

1. *Few Advance Directives are Available and Applicable*

Notwithstanding many government and private initiatives, a majority of Americans do not complete advance directives.<sup>402</sup> Furthermore, even the minority that do complete advance directives often do so in an ineffective manner.<sup>403</sup> First, either the very existence or at least the location of the form is unknown at the time of treatment.<sup>404</sup> Second, even if the form is available, it is often not very informative anyway.<sup>405</sup> After all, "most patients cannot possibly have anticipated and discussed their preferences in the numerous specific clinical states that later may occur."<sup>406</sup>

One notable example of failed surrogate selection is *In re University Hospital of the State University of New York Upstate Medical University*.<sup>407</sup> Providers determined that patient Yvette Casimiro's condition satisfied her

401. See *supra* notes 280 to 284 and accompanying text. See also Kevin B. O'Reilly, *Defective Directives?*, AM. MED. NEWS, Jan. 12, 2009, <http://www.ama-assn.org/amednews/2009/01/05/prsa0105.htm>.

402. See Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 MILBANK Q. 211, 221-28 (2010); see also O'Reilly, *supra* note 401.

403. *Id.*

404. *Id.*

405. *Id.*; Muriel R. Gillick, *The Challenge of Applying Advance Directives in Hospital Practice*, 38 HOSP. PRACTICE 45 (2010).

406. BERNAT, *supra* note 174, at 88. See also *id.* at 92 ("[I]t is ethically justifiable to overrule them . . . because an unexpected deterioration in the patient's health has rendered it no longer applicable."); James L. Bernat & Lynn M. Peterson, *Patient-Centered Informed Consent in Surgical Practice*, 141 ARCHIVES SURGERY 86, 89 (2006); Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?*, 267 JAMA. 59, 62 (1992).

407. *In re Univ. Hosp. of State Univ.*, 754 N.Y.S.2d 153, 154 (N.Y. 2002).

advance directive such that it could invoke her expressed wishes that the life sustaining treatment be terminated.<sup>408</sup> When the surrogates refused to consent, providers went to court.<sup>409</sup> They argued that “by their refusal and unwillingness to cooperate with the removal of these life sustaining systems, [the surrogates] are acting in contravention of the patient’s directions and intent, and, therefore, they should be removed as health care agents. . . .”<sup>410</sup>

But the court refused to replace the surrogate.<sup>411</sup> While the language of the advance directive clearly applied, the court found that it was unclear whether the patient realized the implications of her own advance directive.<sup>412</sup> Furthermore, the court credited the surrogates’ testimony concerning the patient’s “strongly expressed religious beliefs concerning who can take a life.”<sup>413</sup> In short, while advance directives are presumed to be clear and convincing evidence of patient autonomy, that presumption can often be rebutted.

## 2. Patient Preferences Are Rarely Clear and Strong

Just as it may be difficult to establish a contradiction between a surrogate’s decision and a patient’s advance directive, so too it will often be difficult to establish a contradiction between a surrogate’s decision and evidence of patient treatment preferences. The reason, simply, is that there often is no such evidence. Indeed, recognition that surrogates would not have evidence was the point of the laws that gave them rights by status.<sup>414</sup>

The absence of evidence regarding patient wishes is a significant obstacle to surrogate selection. For example, in 2006, Michigan internist Brian Drozdowski asked a Van Buren County probate court “to allow [ninety-seven] year-old Hazel Wagner to be taken off a ventilator and have her feeding tube removed. Wagner, who already had kidney failure and dementia, had recently had a heart attack. In his request, Dr. Drozdowski said that Wagner had no chance of a meaningful recovery” and that it was

408. *Id.* at 154.

409. *Id.* at 153-154.

410. *Id.* at 154.

411. *Id.* at 159.

412. *In re Univ. Hosp. of State Univ.* 754 N.Y.S.2d at 155-158.

413. *Id.* at 157.

414. See Jack Freer & Stephen Wear, *Culture Wars in New York State: Ongoing Political Resistance by Religious Groups to the Family Health Care Decisions Act*, 8 CHRISTIAN BIOETHICS 9, 9-10 (2002) (stating that in New York, surrogates not appointed by a court or advance directive have no status and can consent to stop aggressive treatment only with “clear and convincing” evidence of the patient’s preferences).

unethical to keep her alive in her current condition.<sup>415</sup> “Wagner had left no instructions and, by most accounts, had given no solid verbal indication of whether she would want to be kept alive using a feeding tube or ventilator.”<sup>416</sup> For this reason, the judge denied Dr. Drozdowski’s request and deferred to the surrogate’s decision to continue treatment.<sup>417</sup>

### 3. Patients Want their Surrogates to Have Discretion

As demonstrated in the last two subsections, one serious obstacle to surrogate selection is that the requisite evidence to demonstrate surrogate unfaithfulness is often unavailable.<sup>418</sup> Providers often have no substantial evidence of patient instructions or wishes with which to establish surrogate deviation.<sup>419</sup> But even if there were such evidence, it still might not be sufficient to demonstrate that the surrogate was a maverick.<sup>420</sup>

Surrogates often have permission to deviate from patient instructions and wishes. “Many patients value trust over accuracy” and “prefer that their surrogates exercise judgment in response to actual clinical situations even if the surrogate’s decisions depart from their expressed wishes.”<sup>421</sup> A majority of terminally ill patients would prefer the decision of their surrogate even if it flatly contradicted explicit instructions in their living will.<sup>422</sup>

415. See Bonnie Booth, *Doctor’s Request to End Patient’s Care Denied*, AM. MED. NEWS, June 12, 2006, at 22, 22, available at <http://www.ama-assn.org/amednews/2006/06/12/prca0612.htm>.

416. *Id.*

417. *Id.*

418. See O’Reilly, *supra* note 401.

419. See *id.*

420. Jeffrey T. Berger et al., *supra* note 147, at 49; O’Reilly, *supra* note 401.

421. Jeffrey T. Berger, *When Surrogates’ Responsibilities and Religious Concerns Intersect*, 18 J. CLINICAL ETHICS 391, 392 (2007) (emphasis added); Berger et al., *supra* note 147, at 48. (“[M]any patients do not necessarily want their surrogates to adhere to their specific treatment preferences . . . but instead wish them to respond dynamically . . .”); *id.* at 50 (suggesting that advance directives “should indicate what role the content was intended to serve: binding, weighty but not binding, or merely informative”); J. McCarthy et al., *Irish Views on Death and Dying: A National Survey*, 36 J. MED. ETHICS 454, 455 (2010). See also Nikki Ayers Hawkins et al., *Micromanaging Death: Process Preferences, Values, and Goals in End-of-Life Medical Decision Making*, 45 GERONTOLOGIST 107, 108 (2005); Perkins, *supra* note 157, at 53; Christina M. Puchalski et al., *Patients Who Want Their Family and Physician to Make Resuscitation Decisions for Them: Observations from SUPPORT and HELP*, 48 J. AM. GERIATRICS SOC’Y S84, S85 (2000); Sehgal et al., *supra* note 405, at 59.

422. Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want their Advance Directives Followed?* 267 JAMA 59 (1992); Peter B. Terry et al., *End-of-Life Decision Making: When Patients and Surrogates Disagree*, 10 J. CLINICAL ETHICS 286, 287-90 (1999). Cf. Rebecca L. Sudore, *Can We Agree to Disagree*, 302 JAMA 1629, 1630 (2009) (“[M]y grandfather’s wishes were to have my grandmother make the decision she could live with.”).

While such flexibility does leave more room for error, it is a recognized advantage of surrogates over advance directives.<sup>423</sup> It is difficult for patients to anticipate all the permutations of clinical circumstances in which they might later find themselves. Surrogates, on the other hand, can respond dynamically to each situation and development.

Nevertheless, while it will be difficult to replace a surrogate to whose discretion the patient has deferred, given the low use and availability of advance directives, such surrogates will be rare. Most surrogates are not designated by the patient (with or without discretion), but are clinically designated default surrogates.<sup>424</sup> Therefore, surrogates will often lack sufficient evidence to establish that the patient wanted them to have this discretion.

### C. *Silver Lining: Best Interests Analysis*

It is important to observe that this “lack of evidence” limitation to surrogate selection may be substantially mitigated by the operation of the hierarchical decision-making standards. Specifically, if there is really no evidence of patient instructions or preferences, then neither the subjective standard nor the substituted judgment standard can be applied. In such cases, the appropriate decision-making standard is best interests. In short, the absence of relevant information means reversion to a best interest standard.

As a purely objective standard, healthcare providers are in as good (or perhaps better) position as surrogates to determine the patient’s best interests.<sup>425</sup> They are, after all, more experienced than surrogates at

423. See O’Reilly, *supra* note 401. Some argue that patient-appointed surrogates have a greater moral authority than is now recognized at law. See Joseph J. Fins et al., *Contracts, Covenants, and Advance Care Planning: An Empirical Study of the Moral Obligations of Patient and Proxy*, 29 J. PAIN & SYMPTOM MANAGEMENT 55 (2005).

424. See *supra* notes 132 to 136 and accompanying text. See also Charles P. Sabatino, *The Legal and Functional Status of the Medical Proxy: Suggestions for Statutory Reform*, 27 J.L. MED. & ETHICS 52, 55 (1999).

425. Surrogates are regularly overruled on an application of the best interest standard. Cf. *In re Storar*, 420 N.E.2d 64, 79 (N.Y. 1981) (supporting a mother’s surrogate decision to cease treatment for her mentally incompetent son); Braun et al., *supra* note 69, at 250, 252 (Since surrogates are only “reporters” under the subjective and substituted judgment standards, only under the best interest standard do surrogates engage in “genuine surrogate decision making.”); Robert W. Sibbald & Paula Chidwick, *Best Interests at the End of Life: A Review of Decisions Made by the Capacity and Consent Board of Ontario*, 25 J. CRITICAL CARE 171 (2009). Still, “we must keep in mind that, in the vast majority of situations, the best interests analysis is conducted by a combination of family members and healthcare professionals, and not formally by the courts.” Marshall B. Kapp, *Medical Decision-Making for Incapacitated Elders: A Therapeutic Interest Standard*, \_\_ INT’L J. L. & PSYCH. n.21 (forthcoming 2010).

assessing physical pain and suffering. Take, for example, the case of Mary Grover.<sup>426</sup> Mary suffered a brainstem stroke leaving her quadriplegic, dependent on a ventilator, and with diminished mental function.<sup>427</sup> Her healthcare providers proposed that the focus of Mary's care be comfort only.<sup>428</sup> But Marjorie Grover, Mary's surrogate and the oldest of her ten children, would not consent.<sup>429</sup> Marjorie correctly noted that at the patient's recent nursing home review, G's wish was to receive "full resuscitative measures."<sup>430</sup>

But the CCB still replaced Marjorie as surrogate.<sup>431</sup> The Board noted, "Prior capable wishes are not to be applied mechanically or literally."<sup>432</sup> There was no evidence that Mary had her *current* circumstances in mind or that her wishes were applicable to those circumstances.<sup>433</sup> Moreover, Marjorie's evidence of Mary's values was "quite vague."<sup>434</sup>

Since there were no applicable instructions or evidence of Mary's preferences, the treatment decision had to be determined upon Mary's best interests. In applying this test, the surrogate's decision was accorded no deference. The Board was most influenced by the facts: (1) that Mary's other nine children all agreed with the proposed treatment plan;<sup>435</sup> and (2) that life-sustaining treatments would cause infections and hospitalizations but neither "improve the overall quality of Mary's life nor lessen the disability."<sup>436</sup> Ultimately, the Board deferred to the recommendations of healthcare providers. The Board disregarded Marjorie's decision, finding that she was basing it on "hope" rather than on "experienced medical opinions."<sup>437</sup>

426. *In re G*, 2009 CanLII 25289 (ON C.C.B.); *aff'd*, *In re Grover*, 2009 CanLII 16577 (ON S.C.).

427. *In re Grover*, 2009 CanLII 16577, at 2.

428. *Id.* at 4.

429. *Id.* at 3-4; *In re G*, 2009 CanLII 25289, at 6, 8.

430. *In re Grover*, 2009 CanLII 16577, at 3-4.

431. *In re G*, 2009 CanLII 25289, at 33.

432. *Id.* at 15.

433. *Id.* at 27-28.

434. *Id.* at 29.

435. *Id.* at 29.

436. *In re G*, 2009 CanLII 25289, at 31.

437. *Id.* (The Board also noted that "one of MG's siblings described MG as working her life plans around their mother."). See also *Barbulov v. Huston*, 2010 Ont. Sup. Ct. 2088 (2010) (affirming the CCB on a best interests standard because "family members were misguided by their hope of recovery").

## CONCLUSION

Professor Truog is right to endorse surrogate selection as a solution to intractable futility disputes.<sup>438</sup> It is a mechanism that often works, and one that, when applicable, should be preferred over power-shifting laws. Yet, since surrogate selection cannot resolve significant categories of conflict, we must still develop dispute resolution mechanisms to handle those remaining disputes in which providers conflict with “irreplaceable” surrogates. In short, Truog is right to oppose the empowerment of intramural healthcare ethics committees to adjudicate futility disputes.<sup>439</sup> But he too quickly dismisses proposals for more legitimate, more independent ethics committees.<sup>440</sup>

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438. See Truog *Medical Futility*, *supra* note 20, at 995.

439. See Truog 2007, *supra* note 20, at 2.

440. See *id.* at 1-2; Truog, Correspondence, *supra* note 21, at 1559. I have outlined a dispute resolution mechanism for intractable futility disputes irresolvable through surrogate selection. See Pope, *supra* note 20.