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

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ABSTRACT

This article reviews the strengths and weaknesses of "surrogate selection" as a solution to intractable medical futility disputes. It concludes that while surrogate selection is an increasingly viable solution, it remains only a *partial* solution because it is often difficult or impossible to demonstrate that a surrogate demanding non-recommended end-of-life medical treatment is acting outside the scope of her authority.

Over the past twelve years, many states have been developing new legislative solutions to intractable medical futility disputes. The most widely-discussed solution empowers healthcare providers to unilaterally refuse patient- or surrogate-requested treatment that the provider deems inappropriate. In Texas, for example, when providers and patients' surrogates cannot agree on appropriate life-sustaining medical treatment, the state Advance Directives Act designates the hospital ethics committee as adjudicator of last resort. The Idaho Senate recently passed a bill to the same effect. And policymakers in other states are considering similar legislation.

But Harvard Medical School Professor Robert Truog argues that this too-provider-friendly sort of internal dispute resolution legislation is h unnecessary and dangerous. He argues that current healthcare decisions laws in every state *already* give healthcare providers a 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 providers to designate a new surrogate from whom consent to withhold/withdraw can be obtained.

The logic behind these 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. For example, providers took a surrogate selection approach in the famous *Helga Wanglie* case. Rather than ask the court to make the treatment decision, providers asked the judge only to make a procedural decision appointing a new decision maker. The court-appointed guardian, in turn, would make the substantive decision.

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

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approach. Emblematic of this approach, in a string of published cases during 2008 and 2009, courts from New York to California replaced patients' surrogates because they were demanding inappropriately aggressive end-of-life treatment.

Yet, while surrogate selection has become increasingly well-grounded in both statutory standards and 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, and 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 (for non-beneficial treatment) 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 often 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.

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Introduction

In 2009, the *New England Journal of Medicine* published a very popular interactive clinical case discussion.¹ The case involved a 56-year-old homeless man who was found having a seizure and transported to the hospital. The man was found to have a subarachnoid hemorrhage and acute hydrocephalus. Providers intubated the patient, started mechanical ventilation, and placed a shunt to relieve the hydrocephalus. But cerebral angiography revealed both 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 three days, and both the neurologist and the neurosurgeon opined that the patient 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. The patient's prognosis, at best, was to have a severe disability that would leave him dependent on care by others.

The patient lacked the capacity to make healthcare decisions for himself. While he had not been in contact with his family for several years, he had a son who, under the law of the state, was the patient's legally authorized surrogate decision maker.² The patient also had a brother and a mother. Providers contacted these relatives and apprised them 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.

Accordingly, supportive care, including mechanical ventilation, was continued for the next three weeks. But there was no 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 two weeks. The counselor came to see the patient and related that the patient had told him that he wished to avoid hospitals and that "when his time came" he wanted no aggressive medical care.

Given the lack of improvement in the patient's neurologic state, the extremely poor prognosis for any meaningful recovery of cognitive function, and a (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 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.

² Throughout this article I use 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 Cerminara, The Right to Die § 3.04 (3d ed. Supp. 2010) [hereinafter Right to Die].

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¹ Arthur S. Slutsky et al., *Care of an Unresponsive Patient with a Poor Prognosis*, 360 New Eng. J. Med. 527 (2009); Patricia A. Kritek et al., *Care of an Unresponsive Patient with a Poor Prognosis – Polling Results*, 360 New Eng. J. Med. e15 (2009).

This is a futility dispute. The patient's healthcare providers thought that the only appropriate treatment is comfort care. But the patient's surrogate refused to consent to this recommendation, and instead demanded treatments that, in the providers' judgment, caused more harm than benefit. This sort of conflict regularly occurs in hospitals and other healthcare facilities.³ In the *New England Journal of Medicine* case, it is unclear whether the providers' conflict with the surrogate is intractable. Consequently, many participants in the online poll rightly voted that an ethics consultation was appropriate.⁴ After all, most such disputes are resolved through further communication and mediation.⁵

The focus of this Article is on the avenues for resolution, if the futility dispute later 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.⁶ Physicians are overwhelmingly reluctant to withhold or withdraw treatment without the consent of the authorized decision maker.⁷ Accordingly, without explicit permission to do otherwise, physicians generally comply with surrogate requests for treatment that they think is cruel and wrong.⁸

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

But Harvard Medical School Professor Robert Truog argues that this too-provider-friendly sort of internal dispute resolution legislation is both unnecessary and dangerous. ¹² He argues that current healthcare decisions laws in every state *already*

⁵ Thaddeus Mason 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 (2007).

⁷ See Pope & Waldman, supra note ___, at 179-85.

³ See infra notes __ to __ and accompanying text.

⁴ See supra note 1.

⁶ See infra note ___

⁸ *Id.* at 158-61 (collecting numerous citations). *See also* ALISON BARNES ET AL., COUNSELING OLDER CLIENTS 317 (2d ed. 2005); JOAN M. KRAUSKOPF ET AL., ELDERLAW: ADVOCACY FOR THE AGING § 13:26 (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 et al., *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.").

⁹ Tex. Health & Safety Code § 166.046. See generally Robert L. Fine, The Texas Advance Directives Act of 1999: Politics and Reality, 13 HEC Forum 59 (2001); Thaddeus M. Pope, Legal Briefing: Medical Futility and Assisted Suicide, 20 J. Clinical Ethics 274 (2009).

¹⁰ Tex. Health & Safety Code § 166.045.

¹¹ Idaho S.B. 1114, 60th Legisl., 1st Sess. (2009).

¹² Robert D. Truog, *Tackling Medical Futility in Texas*, 357 New Eng. J. Med. 1 (2007); Robert D. Truog, *Medical Futility*, 25 GA. St. U. L. Rev. 995 (2009); 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 (2009); Robert D. Truog, *Rebuttal From Dr. Truog*, 136 CHEST 972 (2009). In this Article, I focus on Truog's argument that unilateral

give healthcare providers a 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 providers to designate a new surrogate from whom consent to withhold/withdraw can be obtained. Truog argues that since a mechanism like TADA is most useful, and most justified, when surrogates make decisions not in the best interests of patients, the "remedy should be to use existing pathways to challenge the legitimacy of the surrogate to make these decisions and to seek the appointment of another decision maker" 14

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. For example, providers took a surrogate selection approach in the famous *Helga Wanglie* case. 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. This surrogate, in turn, would make the substantive decision (presumably in accordance with provider recommendations).

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.

refusal legislation is unnecessary. 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 (2009).

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¹³ See Jeffrey P. Burns & Robert D. Truog, Futility: A Concept in Evolution, 132 CHEST 1987, 1991-92 (2007); Robert D. Truog, Tackling Futility in Texas, 357 New Eng. J. Med. 1558, 1559 (2007) (endorsing "existing pathways to challenge the legitimacy of the surrogate to make these decisions and to seek appointment of another decision maker"). See also Rasa Gustatis, Right to Refuse Life-Sustaining Treatment, 81 Pediatrics 317, 319 (1988) (suggesting the use of child abuse laws to override parental requests for inappropriate treatment).

¹⁴ Robert D. Truog, *Tackling Medical Futility in Texas [Letter]*, 357 New Eng. J. Med. 1557, 1559 (2007). *See also* Truog, *Counterpoint*, *supra* note ___, at 968 ("I think a better approach would be for clinicians to be more proactive in legally challenging the decisional authority of the surrogates."); Truog, *supra* note ___, at 995 ("When family members insist upon treatment 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 [Webcast]*, Baby Doe Symposium, Georgia State University College of Law,

http://law.gsu.edu/lawreview/index/symposium/spring_2009/videos. *But cf.* Robert Schwartz, *Autonomy, Futility, and the Limits of Medicine,* 1 CAMBRIDGE Q. HEALTHCARE ETHICS 159, 161 (1992) (arguing that the question 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.").

¹⁵ Cf. 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 cases, the physician must ensure . . . that someone who will act in the patient's best interest is named.").

¹⁶ In re Wanglie, No. PX-91-283 (Minn. Prob. Ct. Hennepin County June 28, 1991), reprinted in 7 Issues L. & Med. 369 (1991).

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, in a string of published cases during 2008 and 2009, courts from New York to California replaced patients' surrogates because they were demanding inappropriately aggressive end-of-life treatment.

Finally, in Section Five, I argue that while surrogate selection has become increasingly well-grounded in both statutory standards and 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, and 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.

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. 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." 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," a "right to life," a "duty to die," or even an "involuntary euthanasia" a

^{17.} K. Francis Lee, *Postoperative Futile Care: Stopping the Train When the Family Says "Keep Going,"* 15 THORACIC SURGERY CLINICS 481, 481 (2005).

^{18.} See, e.g., Thomas Wm. Mayo, Living and Dying in a Post-Schiavo World, 38 J. HEALTH L. 587, 602 n.68 (2006); THE RIGHT TO DIE, supra note ___, § 13.01[B], at 13-4.

^{19.} See, e.g., Leigh Middleditch, Jr. & Joel Trotter, The Right to Live, 5 ELDER L.J. 395 (1997) [hereinafter The Right to Live]; Nancy Neveloff Dubler, Conflict and Consensus at the End of Life, HASTINGS CENTER. REP. S19, S19 (Nov.-Dec. 2005); Wesley J. Smith, Suing for the Right to Live, DAILY STANDARD, Mar. 9, 2004.

situation.

One recent futility case is still unfolding before the Court of Queen's Bench of Alberta. In October 2009, Isaiah May was born in Rocky Mountain House, Alberta after a long and difficult 40-hour delivery. At some point, his umbilical chord got wrapped around his neck several times, cutting off the oxygen supply to his brain. Isaiah was airlifted to Stollery Children's Hospital in Edmonton, where he was diagnosed with severe neonatal encephalopathy. He is now dependent on mechanical ventilation. ²³

On January 13, 2010, Alberta Health Services sent Isaiah's parents a letter explaining his prognosis and their planned course of action. The physicians informed the parents that Isaiah would never recover from his severe lack of oxygen at birth. "The diagnosis is unchanged; your son suffered severe anoxic brain injury at birth and has irreversible brain damage. There is no hope of recovery for Isaiah."²⁴

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." 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." 26

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.²⁷ Isaiah's parents argue that continued treatment is appropriate because Isaiah has already defied medical experts by living as long as he has. Moreover, he is showing signs of growth and development.²⁸ The court has not yet ruled on whether the hospital and the physicians may discontinue Isaiah's life support without his parent's consent.

Obviously, baby Isaiah lacks the capacity to make healthcare decisions for himself.²⁹ But even in futility disputes involving *adult* patients, the patient almost always lacks

^{20.} See, e.g., The Right to Live, supra note ___.

^{21.} See Mary Ann Roser, Debate Heats Up on 10-Day Medical Law, Austin Am.-Statesman, Aug. 10, 2006, at B1.

²² Court Adjourns Case of Rocky Couple Fighting to Keep Infant on Life Support, RED DEER ADVOCATE, Jan. 19, 2010; Melissa Dominelli, Parents to Battle AHS, Hospital to Keep their Infant Son on Life Support, CTV EDMONTON, Jan. 19, 2010.

²³ See supra note ___.

²⁴ See supra note ___.

²⁵ See supra note ___.

²⁶ See supra note ___.

²⁷ Andrew Hanon, *More Time to Line up Specialists for Brain-Damaged Baby*, TORONTO SUN, Jan. 29, 2010; Lisa Priest, *Baby Isaiah to Stay on Life Support - for Now*, GLOBE & MAIL, Jan. 28, 2010.

²⁸ Parents Find Expert to Assess Baby on Life-Support, CBC NEWS,

http://www.cbc.ca/health/story/2010/01/27/edmonton-alberta-baby-isaiah-stays-on-ventilator.html#ixzz0e3ygOQLr ²⁹ "Capacity" is typically defined as the "individual's ability to understand the significant benefits, risks and alternatives to proposed health care and to make and communicate a health-care decision." 16 DEL. CODE § 2501(d). See also Ala. Code § 22-8A-11(a)(1)(a) (ability to "understand, appreciate, and direct his or her medical treatment").

capacity. Either because of encephalopathy related to the disorder or because they are sedated, the patient is almost never able to communicate with providers at the time a decision must be made.³⁰ Therefore, these decisions are usually made by surrogates.

In most cases, the surrogate and the health care provider disagree over whether LSMT provides benefit because of a communication failure.³¹ The surrogate and the provider perceive the situation differently.³² In other cases, the disagreement is normative. But, whether for factual or normative reasons, the provider and surrogate disagree because they have different goals.³³ The patient's goals might include cure, amelioration of disability, palliation of symptoms, reversal of disease process, or prolongation of life. The provider, on the other hand, might, under the circumstances, judge these goals to be impossible, virtually impossible, or otherwise inappropriate.³⁴

There is, in short, a demonstrable gap between the goals of physicians and the goals of surrogates. In one recent study, 72% of surrogates think that patients have a right to demand care their physicians think will not help.³⁵ Only 44% of physicians agreed. Similarly, 21% surrogates think that even where doctors think there is "no hope of recovery," all efforts should continue indefinitely. Only 2.5% physicians agree.

1. Physician Reasons for Refusing Requested Treatment.

Healthcare providers have several reasons for wanting to refuse surrogate-requested LSMT.³⁶ First, they want to prevent patient suffering. Aggressive treatment can cause significant pain and suffering. This is unacceptable if there is no countervailing benefit to be achieved by the treatment.³⁷ Continued interventions can be inhumane, invasive, pointless, intrusive, cruel, burdensome, abusive, degrading, obscene, violent, or grotesque.³⁸ CPR, for example, can be painful, causing rib or sternal fractures in

³⁰ See Curtis, supra note ___, at 364; Alexandre Lautrette et al., Surrogate Decision Makers for Incompetent ICU Patients: a European Perspective, 14 CURRENT OPINION IN CRITICAL CARE 714, 715 (2008); Thomas J. Prendergast et al., A National Survey of End-of-Life Care for Critically Ill Patients, 158 Am. J. RESPIRATORY CARE MED. 1163 (1998). But cf. Burke v. Gen. Med. Council [2005] EWCA Civ. 1003, 2 F.C.R. 1223 (patient with capacity litigating a futility dispute concerning his own future treatment).

³¹ See Pope & Waldman, supra note __. See also Anthony Back et al., Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope (2009).

³² See, e.g., David E. Weissman et al., *The Family Meeting: Causes of Conflict*, FAST FACTS AND CONCEPTS 225 (Jan. 2010), available at http://www.eperc.mcw.edu/fastfact/ff 225.htm.

³³ Cf. Thomas Wm. Mayo, Health Care Law, 53 SMU L. REV. 1101, 1110 & n.78 (2000) ("[T]he core dispute is over what constitutes a 'benefit' to the patient").

³⁴ See Thaddeus Mason Pope, Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment, 71 TENN. L. REV. 1, 26-42 (2007) (on definitions of medical inappropriateness).

³⁵ Lenworth M. Jacobs et al., Views of the Public and Trauma Professionals on Death and Dying From Injuries, 143 ARCHIVES SURGERY 730 (2008).

³⁶ There is enormous variability in end-of-life medicine. Some providers actually provide as much as or even more treatment than surrogates desire.

³⁷ Verified Complaint Ex. D to Ex. 1, at 4, Gonzales v. Seton Family of Hospitals, No. A07CA267 (W.D. Tex. Apr. 4, 2007) ("the burdens associated with his current care plan outweigh[ed] any benefit Emilio [might have been] receiving")

³⁸ See, e.g., 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 "I just can't do it to her."); In re Dinnerstein, 380 N.E.2d 134, 134 (Mass. App. 1978) (characterizing LSMT as "pointless, even cruel, prolongation of the act of dying"); In re Doe, 418 S.E.2d 3, 4 (Ga. 1992) (hospital alleged continued treatment would constitute "medical abuse"); Nguyen v. Sacred Heart Med. Center, as reported in John Altomare & Mark Bolde, 11 ISSUES L. & MED. 199, 200 (1995) (hospital alleged

approximately 50% of cases.³⁹ Health care providers want to relieve and shorten patient suffering, not cause or prolong it.⁴⁰

Second, physicians want to protect patient autonomy. In many cases, the aggressive treatment demanded by a surrogate is treatment not wanted by the patient. And even where patient preferences are unknown, continued treatment is not in the patient's best interests. Furthermore, providing unwanted treatment not only violates the patient's bodily integrity but also the patient's autonomy in other respects. It undermines the patient's wishes regarding the location of her death (*e.g.* at home). And it causes the utilization of estate resources to pay medical bills that the patient wanted to go to other uses (e.g. grandchildren education).⁴¹

Third physicians want to prevent family distress. If they acted as though a medically inappropriate option were "available," then that would create a psychological burden on surrogates to elect that option. Atturally, families want to take at least all reasonable measures. Furthermore, it is unfair and deceptive to offer an option where there really is none. Often the surrogate wants the burden of decision lifted from herself. And even if not the surrogate, other family members are often relieved to see the patient's preferences or best interests protected.

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. The medical profession is a self-governing one with its own standards of

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continued treatment was "inhumane"); Appellant Brief, Baby K, 1993 WL 13123742, at *3 ("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."); Martha Kessler, Massachusetts Court Orders Hospital to Comply with Decisions Made under Health Proxy, BNA HEALTH L. REP., 2005 (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, BOST. GLOBE, Mar. 11, 2005 (""[T]his inhumane travesty has gone far enough This is the Masachusetts General Hospital, not Auschwitz."") (quoting Edwin Cassem).

³⁹ See generally Paul C. Sorum, Limiting CPR, 57 ALB. L. Rev. 617, 618 (1994); WRONG MEDICINE, supra note ___, at 94.

⁴⁰ See Capron, supra note ___, at 24 (unilateral termination can avoid "mistreating the patient"); WRONG MEDICINE, supra note ___, at 100-01. Cf. infra note ___.

⁴¹°C. Hogan et al., *Medicare Beneficiaries' Costs of Care in the Last Year of Life*, 20 HEALTH AFFAIRS 188 (2001) (reporting that the average family of a Medicare beneficiary in his or her last year of life pays \$8,000 in out-of-pocket expenses).

⁴² 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 HEC FORUM 276, 281-82 & 285 (2005). But cf. Fletcher, supra note ___, at S:224 (suggesting that the court documents in Baby K showed the physicians had good reasons to intubate).

⁴³ See Howard Brody, *The Physician's Role in Determining Futility*, 42 J. Am. GERIATRIC SOC'Y 875, 876-77 (1994) (unethical to mislead patients by falsely raising hopes); Hudson & Lumsdon, *supra* note ___, at 27 (John Popovich arguing that physicians who offer meaningless care are "charlatans"); Paris et al., *supra* note ___, at 150; Tom Tomlinson & Diane Czlonka, *Futility and Hospital Policy*, HASTINGS CENTER REP., May-June 1995, at 28 (offering futile care is "a bogus choice" and "a deception"); *id.* at 30 (arguing providers should seek "acceptance" of plan rather than "consent").

⁴⁴ Braun et al., *supra* note ___, at 253 ("Requests to 'do everything' should therefore initially be understood as a request for help with managing the surrogate decision-making burden.").

⁴⁵ Robert L. Fine, ___

professional practice. The "integrity of the medical profession" is an important societal interest that must be balanced against patient autonomy. Many health care providers do not consider the practice of medicine to include measures aimed solely at maintaining corporeal existence and the maintenance of biologic functioning. Under these circumstances, providers feel that it is just "wrong" to provide treatment. It is "bad medicine," medicine being used for the wrong ends. Moreover, they find it gruesome, distressing, and demoralizing to provide treatment that harms patients. 48

Fifth, physicians want to reduce moral distress.⁴⁹ Numerous measures show high levels of moral distress among healthcare providers, especially nurses, in situations where they are obligated to provide inappropriate treatment.⁵⁰ This moral distress can both drive people from the profession and thus reduce access.⁵¹ It can also reduce staffing levels and make people operate less well, adversely impacting other patients' quality of care.⁵²

⁴⁶ See generally Washington v. Glucksberg, 521 U.S. 702, 731 (1997); Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 416, 425 (Mass. 1977); In re Quinlan, 355 A.2d 647, 663 (N.J. 1976); Matthew S. Ferguson, Ethical Postures of Futility and California's Uniform Health Care Decisions Act, 75 S. CAL. L. Rev. 1217, 1239-43 (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." ABA MODEL RULES PROF. CONDUCT R. 1.16(b)(4). Lawyers also have obligations under Rule 11 – they cannot file frivolous lawsuits even if the client demands it. See 2 JAMES WM. MOORE, MOORE'S FEDERAL PRACTICE § 11.11 (3d ed. 2003).

⁴⁷ See Benjamin Weiser, Who Should Decide When Treatment Is Futile? In Many Cases, Physicians Are Asking Whether Patient Autonomy Has Gone Too Far: The Case Of Baby Rena, WASH. POST, July 14, 1991, at A19 (quoting Dr. Murray Pollack).

⁴⁸ See 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; Robert A. Burt, The Medical Futility Debate: Patient Choice, Physician Obligation, and End-of-Life Care, 5 J. PALLIATIVE MED. 249, 253 (2002); Hoffman, supra note ("[D]oing CPR [to PVS and end-stage patients] felt not only pointless but like I was administering blows to someone who had already had a hard enough life.") (quoting Dr. Daniel Sulmasy); Terese Hudson & Kevin Lumsdon, Are Futile Care Policies the Answer? Providers Struggle with Decisions for Patients Near the End of Life, 68 HOSPITALS & HEALTH NETWORKS, Feb. 20, 1994, at 26, 27; Rosenthal, supra note ___, at B20 ("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."); 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, Hospital, Family Spar, supra note __ ("Howe's longtime doctors and nurses believe . . . that keeping her alive is tantamount to torture."); Gregory Scott Loeben, Medical Futility and the Goals of Medicine 94 (Unpublished University of Arizona thesis 1999) ("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 "); Weiser, supra note __ (physicians and nurses viewed every day that Baby Rena spent in the ICU as a "day of torture" and "viewed themselves as the torturers"); ZUSSMAN, supra note, , at . Cf. Tom L. 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").

⁴⁹ See generally K.M. Gutierrez, Critical Care Nurses' Perceptions of and Responses to Moral Distress, 24 DIMENSIONS CRITICAL CARE NURSING 229, ____(2005); Ann B. Hamric et al., Moral Distress in Health-Care Providers: What Is It and What Can We Do about It? 69 Pharos Alpha Omega Alpha Honor Med Soc. 16 (2006); Connie M. Ulrich et al., Moral Distress: A Growing Problem in the Health Professions? 40(1) Hastings Center Rep., Jan.-Feb. 2010, at 20.

 ⁵⁰ See, e.g., E. 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 (2003); Ann B. Hamric, Moral Distress and Nurse-Physician Relationships, 12(1) VIRTUAL MENTOR 6 (2010); L.S. Meltzer & L.M. Huckabay, Critical Care Nurses' Perceptions of Futile Care and Its Effect on Burnout, 13 Am. J. CRITICAL CARE 202 (2004).
 ⁵¹ 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 (2007).
 ⁵² See E.H. Elpern et al., Moral Distress of Staff Nurses in a Medical Intensive Care Unit. 14 Am. J. CRITICAL CARE 523 (2005); J.M. Wilkinson, Moral Distress in Nursing Practice: Experience and Effect, 23 Nursing Forum 16 (1988).

Sixth, physicians want to responsibly steward scarce resources. This includes hard resources like ICU beds. In an under-bedded region like New Mexico, the ICU bed used by a patient in a persistent vegetative states with multi-organ failure is the very same bed that could be used to achieve recovery for an accident victim. Physicians are also concerned with stewarding soft resources (e.g. dollars).⁵³ The billions spent treating PVS patients could be used to cover more people who now have no coverage. As costs rise, premiums rise, and access drops.⁵⁴

2. Surrogate Reasons for Requesting Non-recommended Treatment.

While most surrogates accede to provider recommendations to move to comfort care, a significant subset of surrogates are often inclined to request that "everything be done." There are many reasons that surrogates insist on continuing treatment that 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.⁵⁶ Or the distrust might go deeper. Surrogates might distrust that they are receiving proper care either because of their race or socioeconomic status⁵⁷ or because of their provider's financial incentives.⁵⁸ A significant volume of scientific literature demonstrates that patients from racial and ethnic minorities more frequently and more adamantly demand LSMT.⁵⁹

⁵³ But see Lawrence J. Schneiderman & Nancy S. Jecker, *Medical Futility: Response to Critiques*, 125 ANNALS INTERNAL MED. 670, 673 (1996) (arguing that medical futility should have nothing to do with saving money and rationing).

⁵⁴ [Cost inverse to access]

⁵⁵ See, e.g., John Ellement, Woman Suing MGH Tells Court of Distress, Bost. Globe, Apr. 8, 1995, at 18; Donalee Moulton, Death, Denial and the Law, 40 Med. Post [Toronto], May 4, 2004, at 29; LAWRENCE J. SCHNEIDERMAN & NANCY S. JECKER, WRONG MEDICINE: DOCTORS, PATIENTS, AND FUTILE TREATMENT 22-34 (1995) [hereinafter WRONG MEDICINE].

⁵⁶ Zier et al., *supra* note __.

⁵⁷ See, e.g., Pam Belluck, Even as Doctors Say Enough, Families Fight to Prolong Life, N.Y. TIMES, Mar. 27, 2005 (reporting that some "patients and families . . . are skeptical of doctors' interpretations or intentions"); FINS, supra note ___, at 78 ("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 ___, at 483; Kathryn L Moseley et al., Futility in Evolution, 21 CLINICAL GERIATRIC MEDICINE 211, 212-13 (2005) (collecting cites); Mary Ellen Wojtasiewicz, Damage Compounded: Disparities, Distrust, and Disparate Impact in End-of-Life Conflict Resolution Policies, Am. J. BIOETHICS, Sept.-Oct. 2006, at 8-12.

⁵⁸ See Pope & Waldman, supra note __ (collecting cites).

⁵⁹ See generally William Bayer et al., Attitudes toward Life-Sustaining Interventions among Ambulatory Black and White Patients, 16 ETHNICITY & DISEASE 914 (2006); Ursula Braun et al., Decreasing Use of Percutaneous Endoscopic Gastronomy Tube Feedings for Veterans with Dementia – Racial Differences Remain, 53 J. AM.

GERIATRIC SOC'Y 242 (2005); Marion Danis, Improving End-of-Life Care in the ICU: What's to be Learned from the Outcomes Research, 6 NEW HORIZONS 110 (1998); M.N. Diringer et al., Factors Associated with Withdrawal of Mechanical Ventilation in a Neurology/Neurosurgery Intensive Care Unit, 29 CRITICAL CARE MED. 1792-97 (2001); J.M. Garrett et al., Life-sustaining Treatments during Terminal Illness: Who Wants What? 8 J. GEN. INTERNAL MED. 361-68 (1993); K. Fiscella, Socioeconomic Status in Healthcare Outcomes: Selection Bias or Biased Treatment, 42 MED. CARE 939 (2004); F.P. Hopp & S.A. Duffy, Racial Variations in End-of-Life Care, 48 J. AM. GERIATRIC SOC'Y 658-63 (2000); Hilary Waldman, End-of-Life Care, Viewed in Stark Black and White, L.A. Times, Feb. 6, 2006. But see Amber Barnato et al., Racial Variation in End-of-Life Intensive Care Use: A Race or Hospital Effect, 41 HEALTH SERVICES RES. 2219 (2006) (arguing that differences were attributable to the use of hospitals with higher ICU use rather than to racial differences).

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. Easy access to medical information online makes surrogates more confident in opposing providers' recommendations. Even in the face of clear and dire medical facts, family members often hold out hope that the patient will beat the odds. In one study, 32% of surrogates elected to continue treatment for patients with less than 1% survival estimate. 18% elected to continue treatment when the physician felt there was no chance of survival.

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, as many non-professionals do,⁶⁴ that God will perform a miracle.⁶⁵ Or they might otherwise be compelled by religious or cultural traditions.⁶⁶ Disputes involving surrogates somotivated tend to be the most intractable.⁶⁷

⁶⁰ 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 n.5 & 26 n.153 (2005) (discussing "therapeutic illusions" where patients have "false hopes despite the lack of future benefit"); Middleditch & Trotter, supra note __, at 402-03 (discussing "society's increasing denial of death").

⁶¹ Julie Sneider, *Medical Ethics Experts See Shift in Care Disputes*, MILWAUKEE BUS. J., Apr. 22, 2005.
62 See Todd Ackerman, *Leukemia Patient's Parents Scramble to Find New Care Facility*, HOUS. CHRON., Apr. 29, 2005 (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 believes "I think she can beat the odds . . . she's a fighter."); Belluck, *Families Fight, supra* note __ ("Extraordinary medical advances have stoked the hopes of families."); Clare Dyer, *Doctors Need Not Ventilate Baby to Prolong Life*, 329 BMJ 995 (2004) (reporting that mother of 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 37 (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 daughter, we could not but hold to such a faith.").

⁶³ Zier et al., *supra* note ___.

⁶⁴ Jacobs et al., *supra* note ___

⁶⁵ 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 ___, at 483; Ed Yeates, Parents Fight to Keep Son on Life Support, KSL TV5, Oct. 13, 2004 (parents sought an injunction to stop physicians from disconnecting their son from life support even though he was declared dead because "we performed a miracle and I don't see why we can't do that again"); Parents Fear Home Delay May Keep Miracle Baby Charlotte in Hospital, BIRMINGHAM POST [UK], Jan. 7, 2006 (reporting that parents of Charlotte Wyatt "are committed Christians" who believe that "miracles do happen").

⁶⁶ See, e.g., Rideout v. Hershey Med. Ctr., 30 Pa. D. & C.4th 57, 62 (Pa. Common Pleas Ct., Dauphin Cty. 1995) (parents opposed to removing ventilator from daughter because of "religious belief that all human life has value and should be protected"); Brief of Appellant, *In re Achtabowski*, No. 93-1247-AV (Mich. Cir. Ct. Aug. 12, 1993) (No. 170251), at 39 ("I cannot make that decision to terminate life. God did not give me that power.") (quoted by 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 (1994)); Bill Murphy, *Comatose Man Dies after Battle over Life Support*, HOUS. CHRON., Mar. 23, 2001, at A29 (reporting that for "spiritual and cultural reasons," the family of Joseph Ndiyob sought an injunction preventing Memorial Hermann Hospital from removing Ndiyob's life support); John Carvel, *Muslim Family Loses Right-to-Life Appeal*, GUARDIAN UNLIMITED, Sept. 2, 2005 (noting the "family's religious conviction"); Lee, *supra* note __, at 483; Emily Ramshaw, *Children Fight to Save Mom*, DALLAS NEWS, Aug. 18, 2006 ("Ruthie Webster is deeply religious and believes only God should give and take life."); Benjamin Weiser, *The Case of Baby Rena: a Question of Letting Go: Who Should Decide when Treatment is Futile?* WASH. Post, July 14, 1991 (discussing the religious views of Baby Rena's father).

⁶⁷ Lucas S. Zier et al., Surrogate Decision Makers' Responses to Physicians' Predictions of Medical Futility, 136 CHEST 110 (2009).

Fourth, surrogates may feel a sense of responsibility or guilt with respect to their relationship to the patient.⁶⁸ They might be too grief stricken to stop treatment.⁶⁹ Or they might -- consistent with the "technological imperative" in American medicine⁷⁰ -- simply have a sense that the patient is entitled to everything.⁷¹ Whatever the reason, more and more surrogates want their health care providers to "do everything."

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" ⁷³ And the numbers are beginning to bear this out. ⁷⁴ Nearly one-third of ICU patients had conflicts associated with their care. ⁷⁵

⁶⁸ Jan Hoffman, *The Last Word on the Last Breath*, N.Y. TIMES, Oct. 10, 2006 ("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 ___, at 483; John J. Paris et al., *Has the Emphasis on Autonomy Gone Too Far? Insights from Dostoevsky on Parental Decisionmaking in the NICU*, 15 CAMBR. Q. HEALTHCARE ETHICS 147, 147 (2006); Ann Wlazelek, *Hospital Procedures Made Clear at Women's Expense*, KANSAS CITY STAR, June 12, 2004 ("'It's dangerous to give the family the last word since guilt and a desire to do everything for pop makes it emotionally impossible to stop treatment.") (quoting Arthur Caplan).

⁶⁹ See, e.g., Alexander Morgan Capron, *Abandoning a Waning Life; Right to Die*, HASTINGS CENTER REP., July 1995, at 24 (reporting that Mass. 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, 2067 (1992) (family members find that they cannot "let the patient go").

⁷⁰ This is the mindset that because we *can* use a given technology, we *should* use that technology. *See generally* V.R. FUCHS, WHO SHALL LIVE? HEALTH ECONOMICS AND SOCIAL CHOICE (1974); 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); Robert L. Fine, <i>The History of Institutional Ethics at Baylor University Medical Center*, 17 BAYLOR UNIV. MED. CTR. PROC. 73, 73 (2004).

⁷¹ See, e.g., A. Kopelman, supra note __, at 582-85; Alan Meisel, The Role of Litigation in End-of-Life Care: A Reappraisal, HASTINGS CENTER REP., Nov.-Dec. 2006, 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 __, at 392; James W. Walter, Medical Futility – an Ethical Issue for Clinicians and Patients, PRACTICAL BIOETHICS, Summer 2005, at 1, 1 & 6. 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). See also Todd Ackerman, St. Luke's Postpones Removal of Life Support, HOUS. CHRON., Mar. 12, 2005 ("[T]he family understands there is no hope . . . [but] the decision when life support is removed should be ours, not a corporation's.").

⁷² See Pew Research Center for the People and the Press, More Americans Discussing – and Planning – End-of-Life Treatment: Strong Public Support for Right to Die 24 (2006) (reporting that between 1990 and 2005, the percent of Americans who want a doctor to "do everything" increased from 15% to 22%). See also Sneider, supra note __ ("[M]ore families are challenging doctors who believe additional medical treatment of a critically ill patient is unwarranted."). [add Archives Surgery]

⁷³ RIGHT TO DIE, *supra* note ___, at § 13.01[D].

⁷⁴ See, e.g., Pam Belluck, Even as Doctors Say Enough, Families Fight to Prolong Life, N.Y. TIMES, Mar. 27,2005, at Al ("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, 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 III Patients in the United States, 175 Am. J. RESPIRATORY & CRITICAL CARE MED. 1104, 1104-07 (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 18, 2009 ("This scenario is a composite of cases . . . that 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 CLIN. PROC. 686, 689-90 (2007) (finding that futility disputes are one of the primary reasons for hospital ethics consultations).

One recent study identified 974 futility disputes in sixteen hospitals over an average four-year period. 76

Futility disputes are regularly identified as the single biggest ethical dilemma facing North American hospitals.⁷⁷ They constitute a top healthcare ethics challenge now facing the public.⁷⁸ The debate over who decides when continued LSMT is inappropriate is "one of the most important and contentious in medical ethics." It has become a "pressing issue of our times, whether we like it or not!" 80

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."81 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, 57% of surrogates agreed immediately with a provider-recommended care-plan, and 90% moved toward agreement within five days. 82 In a more recent study, Garros and colleagues found that consensus was reached in 51% of cases at the first meeting, in 69% of cases after a second meeting, and in 97% of cases after a third meeting.⁸³ In an even broader study of nearly 3000 disputes, consensus was reached in all but 65.84

In short, futility disputes are "usually resolved collaboratively by the treatment team and the family."85 Even when not settled there, "multi-disciplinary ethics consultation helps families accept treatment limitation" in nearly 90% of cases. 86 The focus of this article is on the remaining intractable disputes: "How to proceed when impasse persists

⁷⁵ Nathalie Danjoux Meth et al., Conflicts in the ICU: Perspective of Administrators and Clinicians, 35 INTENSIVE CARE MED. 2068, 2069 (2009) (reviewing six studies); Alexia M. Torke et al., Physicians' Experience with Surrogate Decision Making for Hospitalized Adults, 24 J. GEN. INTERNAL MED. 1023, 1026 (2009).

⁷⁶ 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 A1.

Death and Dying: When Is It Time to Let Go? CNN.com/living, July 31, 2007.

⁷⁸ Jonathan M Breslin et al., Top 10 Health Care Ethics Challenges Facing the Public: Views of Toronto Bioethicists, 6 BMC MED. ETHICS (2005).

⁷⁹ Steven H. Miles, *Medical Futility*, 20 LAW MED HEALTH CARE 310-15 (1992).

⁸⁰ AYUL M. ZAMIR, INTERN BETH 157 (2006).

⁸¹ A.A. Eduard Verhagen et al., Conflicts about End-of-Life Decisions in NICUs in the Netherlands, 124 PEDIATRICS e112, e117 (2009).

⁸² Prendergast et al., supra note __, at 1165; see also Thomas J. Prendergast, Resolving Conflicts Surrounding End-

of-Life Care, 5 New Horizons 62, 67 (1997).

83 Daniel Garros, Circumstances Surrounding End of Life in a Pediatric Intensive Care Unit. 112 PEDIATRICS e371,

⁸⁴ Robert L. Fine, Point: The Texas Advance Directives Act Effectively and Ethically Resolves Disputes About Medical Futility, 136 CHEST 963.

⁸⁵ Robert L. Fine, Tackling Medical Futility in Texas, 357 New Eng. J. Med. 1558, 1558 (2007) (citing Fine & Mayo 2003) ("[B]asic clinical ethics consultation alone . . . brought closure to . . . 86% of explicit futility cases."). ⁸⁶ Id.

remains an unsettled controversy."87 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."88

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. For the sake of clarity and economy, I refer to this substitute decision maker as a "surrogate." 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.

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. 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." Second, the court can appoint a surrogate. This type of surrogate is normally referred to as a "guardian" or "conservator." 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." 91

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 they become unable to decide for themselves. 92 This appointment can be made through a simple form typically referred to as an advance directive or durable power of attorney for healthcare.

⁹⁰ See generally THE RIGHT TO DIE, supra note ___, at §§ 8.01-8.11 (outlining the jurisprudence of selecting surrogate decision makers).

⁸⁷ Siegel, *supra* note ___, at 189.

⁸⁸ Bruce Jennings, Ethical Dilemmas in Surrogate Decision Making, in ETHICAL DILEMMAS AT THE END OF LIFE 157,

⁸⁹ See supra note 2.

^{91.} 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). Cf. Sumeeta Varma & David Wendler, Medical Decision Making for Patients without Surrogates, 167 ARCHIVES INTERNAL MED. 1711, 1712 (2007); Douglas B. White et al., Life Support for Patients without a Surrogate Decision Maker: Who Decides?, 147 Annals Internal Med. 34 (2007).

² See generally THE RIGHT TO DIE, supra note $_$.

Furthermore, even if a patient has not undertaken the execution formalities to appoint an agent, they can often designate a surrogate, even orally. Such a designation is made directly by the patient to healthcare providers, letting them know whom the patient wants to speak on her behalf.⁹³

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. And providers must comply with the healthcare decisions made in good faith by an agent to the same extent as decisions made by the patient.

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 (sometimes called a proxy). The provider makes the designation on the patient's behalf pursuant to default surrogate statutes in almost every state. These statutes specify a priority list of individuals whom the physician should or must designate. Typically, at the top of this hierarchy are the patient's spouse, adult child, parent, and adult sibling. These relatives are likely not only to know the convictions and beliefs of the patient but also to be concerned for the patient. Since most patients do not engage in adequate advance care planning, default surrogates are the most numerous type of surrogate.

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. 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. ⁹⁹ Because this

⁹³ See, e.g., Alaska Stat. § 13.52.030; Cal. Probate Code § 4714; Del. Code Ann. tit. 16, § 2507; Hawaii Rev. Stat. §§ 327E-2 & E-5; Miss. Code Ann. §§ 41-41-201 to -229. See generally Sabatino, supra note ___, at 22. ⁹⁴ This type of surrogate is sometimes referred to as a "proxy." Fla. Stat. § 765.401.

⁹⁵ New York and Missouri currently lack effective mechanisms for physician-designation of surrogates. *See* Pope, *supra* note ___, at 362.

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. Ann. § 15-18.5-101 to -103; Mich. Comp. Laws Ann. §§ 333.5651 to 5661; Tenn. Code Ann. §§ 68-11-1801 to -1815. North Dakota limits to relative "who has maintained significant contacts" with the patient. N.D. Cent. Code § 23-12-13.

⁵⁷ 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 A Family Divided Leaves Life-or-Death Decision to Man's Guardian*, VA. LAW. WEEKLY, Sept. 8, 2003. Such situations are outside the scope of this article.

⁹⁸ Alan Meisel & Bruce Jennings, *End-of-Life Care and the Law: Overview, in EthICAL DILEMMAS AT THE END OF LIFE 63*, 72 (2005).

⁹⁹ Guardians often have a far broader scope of authority than agents or default surrogates because they are often guardians not only of the person but also of the person's property. This can also be accomplished through a general (non-healthcare-specific) durable power of attorney. [cite]

process can be cumbersome and expensive, comparatively few surrogates are guardians. 100

B. Duties of Surrogates

Whether patient-, physician-, or court-designated, a surrogate is an "extension of the patient". 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 . . . "102 The surrogate is "obligated to suppress his or her own judgment in favor of 'channeling' what the [patient] would have done."103 A well respected how-to guide for surrogates advises them "to decide as the patient would, *even if* the decision goes against the way you would decide for yourself."104

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

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

¹⁰⁰ See Meisel & Jennings, supra note ___, at 72.

¹⁰¹ AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS § 8.081.

¹⁰² In re Browning, 565 So. 2d 4, 13 (Fla. 1990). Frolik, *supra* note __, at 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").

¹⁰³ Frolik, *supra* note ___, at 65. *See also* RESTATEMENT (THIRD) OF AGENCY § 8.01 cmt. b ("The 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, 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").

¹⁰⁴ ABA COMMISSION ON LAW & AGING, MAKING MEDICAL DECISIONS FOR SOMEONE ELSE: A HOW-TO GUIDE 4 (2009) (emphasis added); *see also* Jennings, *supra* note __ 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.").

¹⁰⁵ See Frolik, supra note ___, 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 ch.11 (1991 & Supp. 2007) (explaining various methods for surrogate decision-making).

¹⁰⁶ See, e.g., WIS. STAT. § 155.20(5) ("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.").

¹⁰⁷ RIGHT TO DIE, supra note __ § 4.01[b]-[c].

¹⁰⁸ James L. Bernat, *Ethical Issues in the Treatment of Severe Brain Injury*, 1157 ANN. N.Y. ACAD. SCI. 117, 123 (2009). Admittedly, the *de facto* standard is agreement. RIGHT TO DIE, *supra* note ___ ' 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. 2008, *supra* note __. 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 futility disputes.

circumstances. Such instructions are normally memorialized in an advance directive or a living will. In such cases, the advance directive becomes a "self-initiating consent document." 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. The surrogate is charged merely with implementing what the patient has already "actually decided." 112

In such situations, the surrogate's discretion is normally constrained by the patient's written instructions. Massachusetts, 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." 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.

2. Substituted Judgment: Implement the Patient's Preferences

While theoretically the most straightforward standard, the circumstances rarely obtain for application of the subjective standard. First, few patients have left specific treatment instructions. Second, even when patient have memorialized written instructions, they are often unavailable at the time a decision must be made. Third, even when instructions are available, they often fail to address the situation at hand.

¹⁰⁹ 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" part indicates the person's wishes regarding treatment and care.

¹¹⁰ Casey Frank, Surrogate Decision-Making for 'Friendless' Patients, 34(4) Colo. Law. 71, 71 (Apr. 2005).

¹¹¹ Ursula K. Braun et al., *Reconceptualizing the Experience of Surrogate Decision Making: Reports vs Genuine Decisions*, 7 Annals Fam. Med. 249, 250 (2009).

¹¹² See generally RIGHT TO DIE, supra note __ § 4.05; ALA. CODE § 22-8A-6 ("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.").

 $^{^{113}}$ This is true unless the patient specifically granted otherwise. See infra notes __ to __ and accompanying text. 114 MASS. GEN. LAWS ch. 201D § 5.

¹¹⁵ 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").

¹¹⁶ CHARLES P. SABATINO, ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: LEGAL AND POLICY ISSUES 10-12

CHARLES P. SABATINO, ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: LEGAL AND POLICY ISSUES 10-12 (DHHS 2007). Only 30% of Americans have an advance directive. *Harris Interactive for the ABA* (April 2008). Even among terminally ill patients the completion rate is under 50%. *Honoring Final Wishes: How to Respect Americans' Choices at the End of Life*, HEARING BEFORE THE U.S. SENATE SPECIAL COMMITTEE ON AGING (Sept. 24, 2008).

Not only have advance directives been completed by only a minority of the population but also most of the advance directives in that subset are ineffective because either their existence or location is unknown. Roughly 70% of physicians whose patients do have advance directives do not know they exist. [cite]

118 As discussed below, this is demanding because it requires that the instructions (1) be directed at the treatment in

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 __§ 4.06[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. 50 (2007). 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*, 34

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. 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."

In describing the substituted judgment standard, the AMA Code of Medical Ethics states:

This entails considering the patient's advance directive (if any),¹²¹ 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.¹²²

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

The law in other states is substantially similar. 124 Massachusetts, for example, provides: "the agent shall make health care decisions in accordance with the

HASTINGS CENTER REP., Mar.-Apr. 2004, at 30; D.P. Hickey, *The Disutility of Advance Directives: We Know the Problems, but Are There Solutions?* 36 J. HEALTH L. 455 (2003); NICHOLAS A. CHRISTAKIS, DEATH FORETOLD: PROPHECY AND PROGNOSIS IN MEDICAL CARE (Univ. Chicago 1999). On the other hand, better informed consent tools appear able to address some of these problems. *See, e.g.*, Angelo 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 (2009); Angelo Volandes, *Overcoming Educational Barriers for Advance Care Planning in Latinos with Video Images*, 11 J. Palliative Med. 700 (2008).

¹¹⁹ See RIGHT TO DIE, supra note __ § 4.02; Longeway, 549 N.E.2d at 299 (Ill. 1989) ("Where no clear intent exists, the patient's personal value system must guide the surrogate.").

¹²⁰ CODE OF MEDICAL ETHICS, *supra* note __ § 8.081.

¹²¹ If the advance directive specifically addressed 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.

¹²² CODE OF MEDICAL ETHICS, *supra* note __ § 8.081. *See also id.* § 2.20 ("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.").

¹²³ ALA. CODE § 22-8A-11(c); *see also id.* § 22-8A-6.

¹²⁴ See, e.g., MD. CODE ANN., HEALTH-GEN. § 5-605(c)(1); In re Westchester County 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.").

agent's assessment of the principal's wishes, including the principal's religious and moral beliefs." ¹²⁵

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. In the absence of patient-centric evidence, the surrogate must rely on more objective grounds. This decision-making criterion is referred to as the "best interest standard." 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.¹²⁸

The law across the United States is substantially similar. Massachusetts, for example, provides: "if 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." ¹²⁹

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.¹³⁰

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 impairment that may result from treatment.¹³¹

1.

¹²⁵ Mass. Gen. Laws ch. 201D § 5.

¹²⁶ See, e.g., FLA. STAT. ANN. § 765.205(1)(b) ("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) ("[I]f the wishes of the patient are unknown or unclear, [base decisions] on the patient's best interest.").

¹²⁷ RIGHT TO DIE, *supra* note __ § 4.07.

¹²⁸ See Code of Medical Ethics, supra note __ § 8.081 (emphasis added). See also Id. § 2.20 (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.").

¹²⁹ MASS. GEN. LAWS ch. 201D § 5 (also requiring "full consideration of acceptable medical alternatives").

¹³¹ CODE OF MEDICAL ETHICS, *supra* note __ § 8.081; *see also* Frolik, *supra* note __, at 71 ("The best interest standard is in effect a signal of 'best practices."").

Other factors a surrogate might consider include: (i) the patient's physical, sensory, emotional, and cognitive functioning; (ii) quality of life, (iii) life expectancy; (iv) the prognosis for recovery with and without treatment; (v) various treatment options; (vi) the degree of humiliation, dependence, and loss of dignity resulting from the condition and treatment. ¹³² In the futility context, "[a] patient's preservable existence might be so tortuous, painful, or filled with suffering that it would be deemed inhumane for a surrogate to dictate continued medical intervention." ¹³³ Even permanent unconsciousness is increasingly broadly recognized as a status in which a patient can derive zero benefit from continued LSMT. 134

Notably, the *Code* specifically anticipates that surrogates might be guided by irrelevant concerns, and 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."¹³⁵

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. 136 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. 137

A. Surrogate Performance Is Mediocre.

ABA slide 10 desirable attributes of surrogate. Unfortunately, surrogates often perform rather poorly. They either do not know patient preferences or do not follow them.

134. Id. at 884-85.

¹³² See Woods v. Kentucky, 142 S.W.3d 24, 35 (Ky. 2004). In a surprising application of the best interest test, the Kentucky Court of Appeals held 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 (Ky. Ct. App.

^{133.} Cantor, *supra* note , at 884.

¹³⁵ CODE OF MEDICAL ETHICS, *supra* note ___ § 8.081 (emphasis added). *See also* BERNAT, *supra* note ___, at 89 ("The best interest standard . . . attempts to be objective, [but] remains inherently subjective."); Lawrence A. Froilik, Is a Guardian the Alter Ego of the Ward? 37 STETSON L. REV. 53, 61 (2007) ("How does the guardian choose . . . doing what the guardian might think best based upon the values of the guardian . . . 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.").

¹³⁶ See generally Robert S. Olick & Paul W. Armstrong, Health Care Directives, 15B New Jersey Practice., Legal FORMS § 37:29 (4th ed. 2009) ("In practice the health care proxy will not always adequately represent the patient's interests."); Sections III & IV, *infra*. . ¹³⁷ 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 mayerick agent can expose the provider to liability. See, e.g., Scheible v. Joseph L. Morse Geriatric Center (Palm Beach Cty., Fla. 2007); Holly Fernandez Lynch et al., Compliance with Advance Directives: Wrongful Living and Tort Law Incentives, 29 J. LEGAL MED. 133 (2008); Kathleen E. Wherthey, Cause of Action to Recover Damages for Health Care Provider's Failure to Comply with Advance Directive, 16 Causes of Action 2d 83 (2008).

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. A recent meta-review of sixteen studies indicated that, overall, surrogates predict patient's treatment preferences with just 68% accuracy. A more recent study found even lower accuracy. Indeed, these are hardly new findings. This same dubious surrogate performance has been repeatedly measured and documented for over two decades.

¹³⁸ K.A. Bramstedt, Questioning the Decision-Making Capacity of Surrogates, 33 INTERNAL MED. J. 257 (2003); 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 (2003); Moorman & Carr, supra note, at 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, Predictors of Patient Treatment Preferences and Spouse Substituted Judgments: The Case of Dialysis Continuation 26 MEDICAL DECISION MAKING 112 (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' condition): W.D. Smucker, Modal Preferences Predict Elderly Patients' Life-Sustaining Treatment Choices as well as Patients' Chosen Surrogates Do. 20 MED. DECISION MAKING 271 (2000). See also RIGHT TO DIE, supra note \$\,\\$ 3.16[c][2]; M. Ciroldi et al., Ability of Family Members to Predict Patient's Consent to Critical Care Research, 33 Intensive Care Med. 807 (2007); M. Coppolino & L. Ackerson, Do Surrogate Decision Makers Provide Accurate Consent for Intensive Care Research? 119 CHEST 603 (2001); Nina A. Kohn & Jeremy A. Blumenthal, Designating Health Care Decision Makers for Patients Without Advance Directives: A Psychological Critique 18-20 (2008); A.V. Mantravadi et al., Accuracy of Surrogate Decision Making in Elective Surgery, 33 J. CATARACT & REFRACTIVE SURGERY 2091 (2007). But see Mats Johansson & Linus Brostrom, Turning Failures into Successes: a Methodological Shortcoming in Empirical Research on Surrogate Accuracy, 29 Theoretical Med. & BIOETHICS 17 (2008) (addressing a methodological shortcoming evident in a significant number of studies on substitute decision-making); Linus Brostrom & Mats Johansson, Surrogates Have Not Been Shown to Make Inaccurate Substituted Judgments, 20 J. CLINICAL ETHICS 266 (2009) (same); Mats Johansson & Linus Brostrom, Counterfactual Reasoning in Surrogate Decision Making – Another Look, __ BIOETHICS (forthcoming 2010). ¹³⁹ David I. Shalowitz et al., The Accuracy of Surrogate Decision Makers, 166 Archives Internal Med. 493 (2006) (surrogate accuracy in dementia scenarios was only 58%).

¹⁴⁰ Ines 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%").

¹⁴¹ See, e.g., Ezekiel Emanuel & Linda E. Emanuel, *Decision Making for Incompetent Patients: An Ethical and*

¹⁴¹ See, e.g., Ezekiel Emanuel & Linda E. Emanuel, Decision Making for Incompetent Patients: An Ethical and Empirical Analysis, 267 JAMA 2067 (1992); J. Hare et al., Patient Centered Approach to Advance Care Planning in the Nursing Home, 47 J. Am. Geriatrics Soc'y 227 (1999); J. Hare et al., Agreement Between Patients and Their Self-Selected Surrogates on Difficult Medical Decisions, 152 Archives Internal Med. 1049 (1992); P.M. Layde et al., Surrogates' Prediction of Seriously Ill Patients' Resuscitation Preferences, 4 Archives Family Med. 518 (1995); J.G. Ouslander, Health Care Decisions Among Elderly Long-Term Care Residents and their Potential Proxies, 149 Archives Internal Med. 1367 (1989); Robert A. Pearlman et al., Spousal Understanding of Patient Quality of Life: Implications for Surrogate Decisions, 3 J. Clinical Ethics 114 (1988); A.B. Seckler et al., Substituted Judgment: How Accurate Are Proxy Predictions? 115 Annals Internal Med. 92 (1991) (finding patient-surrogate agreement just 59% of the time); J. Suhl, Myth of Substituted Judgment: Surrogate Decision Making Regarding Life Support Is Unreliable, 154 Archives Internal Med. 90 (1994); Daniel P. Sulmasy et al., The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses, 128 Annals Internal Med. 621 (1998); N.R. Zweibel & C.K. Cassel, Treatment Choices at the End of Life: A Comparison of Decisions by Older Patients and their Physician-Selected Proxies, 29 Gerontologist 615 (1989).

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. In other words, a surrogate is more likely to request aggressive life-sustaining treatment for a patient than the patient would for herself. Therefore, in many futility disputes, the treatment that providers want to refuse is treatment that the patient 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. Patients themselves do not reflect on their end-of-life care, so it is unclear that they have even formed preferences to communicate to surrogates. This is only exacerbated by the fact that patient preferences change over time. 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. "We cannot ignore the possibility that a surrogate might act contrary to the wishes of the patient." "148

¹⁴² See P.H. Ditto et al., Advance Directives as Acts of Communication: A Randomized Controlled Trial, 161 ARCHIVES INTERNAL MED. 421 (2001); J. Hare et al., Agreement between Patients and their Self-Selected Surrogates on Difficult Medical Decisions, 152 ARCHIVES INTERNAL MED. 1049 (1992) (finding patient-surrogate agreement only 70% of the time); Robert A. Pearlman et al., Spousal Understanding of Patient Quality of Life: Implications for Surrogate Decisions, 3 J. CLINICAL ETHICS 114, 119 (1992); Shalowitz, supra note __; Jeremiah Suhl et al., Myth of Substituted Judgment, 154 ARCHIVES INTERNAL MED. 90, 94 (1994); Richard F. Uhlmann et al., Physicians' and Spouses' Predictions of Elderly Patients' Resuscitation Preferences, 43 J. GERONTOLOGY M115 (1988) (finding that spouses overestimated patients' preferences for resuscitation decisions, significantly so in some situations).

¹⁴³ Husbands commit significantly more overtreatment errors than did wives acting as surrogates. 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).

¹⁴⁴ See Betty S. Black et al., Surrogate Decision Makers' Understanding of Dementia Patients' Prior Wishes for Endof-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"); Terri R. Fried et al., Understanding Advance Care Planning as a Process of Health Behavior Change, 57 J. Am. Geriatrics Soc'y 1547 (2009). On the other hand, some evidence suggests that this would not improve the rate of agreement. See Shalowitz, supra note ___.

suggests that this would not improve the rate of agreement. See Shalowitz, supra note __.

145 See L. Harmon, Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment, 100 YALE L.J. 1 (1990).

¹⁴⁶ See M.N. Wittink et al., Stability of Preferences for End-of-Life Treatment after 3 Years of Follow-Up, 168 ARCHIVES INTERNAL MED. 2125 (2008).

¹⁴⁷ Kohn & Blumenthal, *supra* note ___, at 18-20. This is exacerbated by physicians who ask surrogates what "they want to do" for the patient rather than "what would the patient have chosen." ¹⁴⁸ *Browning*, 565 So. 2d at 15.

First, surrogates frequently do not understand the clinical status of the patients whom they represent.¹⁴⁹ "Less than half, regardless of educational level, had adequate knowledge of what was going on and what would happen [to the patient]."150 Both for this reason and due to a belief in miracles, nearly 90% of surrogates doubt the physician's prognosis. 151 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. These psychological problems may impair the surrogate's own decision-making capacity. 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." In short, "serious question arises about the surrogate's fitness to serve."155

Third, surrogates often cannot distinguish their own preferences from those of the patient."¹⁵⁶ There are two leading psychological explanations for this tendency. Surrogates may act on "assumed similarity," assuming that she and the patient hold

¹⁴⁹ R.M. Rodriguez et al., A Prospective Study of Primary Surrogate Decision Makers' Knowledge of Intensive Care, 36 CRITICAL CARE MED. 1633 (2008).

¹⁵⁰ James W. Jones & Lawrence B. McCullough, *Dominions of Surrogate Opinions: Who Is in Charge?* 49 J. VASCULAR SURGERY 249, 249 (2009).

¹⁵¹ Lucas 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 (2008).

152 See generally E. 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 (2005); M.A. Jezewski & D.S. Finnell, The Meaning of DNR Status: Oncology Nurses Experiences with Patients and Families, 21 CANCER NURSING 212 (1998); Jennifer L. McAdam & Kathleen Puntillo, Symptoms Experiences by Family Members of Patients in Intensive Care Units, 18 Am. J. CRITICAL CARE 200 (2009); M.C. Poncet et al., Burnout Syndrome in Critical Care Nursing Staff, 175 AM. J. RESPIRATORY & CRITICAL CARE MED. 698 (2007); F. 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 (2005): F. Pochard et al., Symptoms of Anxiety and Depression in Family Members of Intensive Care Unit Patients: Ethical Hypothesis Regarding Decision-Making Capacity, 29 CRITICAL CARE MED 1893 (2001); 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 (2008); V.P. Tilden et al., Family Decision Making to Withdraw Life-Sustaining Treatments from Hospitalized Patients, 50 Nursing Research 105 (2001).

¹⁵³ See RIGHT TO DIE, supra note __ § 3.17; Thomas J. Prendergast, Resolving Conflicts Surrounding End-of-Life Care, 5 New Horizons 62, 67 (1997).

¹⁵⁴ Olick & Armstrong, *supra* note ___.
155 RIGHT TO DIE, *supra* note ___ § 3.24[c].

¹⁵⁶ See Angela Fagerlin et al., Projection in Surrogate Decisions about Life-Sustaining Treatments, 20 HEALTH PSYCH. 166 (2001). 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 (2005); Collins et al., The State of Advance Care Planning: One Decade after SUPPORT, 23 AM. J. HOSPICE & PALLIATIVE CARE 378 (2006); 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 would want for the patient and what the patient would want for himself or herself."); Sara M. Moorman & Deborah Carr, Spouses' Effectiveness as Endof-Life Health Care Surrogates: Accuracy, Uncertainty, and Errors of Overtreatment or Undertreatment, 48 THE GERONTOLOGIST 811, 812 (2008) (citing Sara M. Moorman et al., Do Spouses Know Each Other's End-of-Life Treatment Preferences? (University of Wisconsin-Madison Center for Demography and Ecology, working paper 2007-05); Rachel A. Pruchno et al., Spouse as Health Care Proxy for Dialysis Patients: Whose Preferences Matter? 45 The Gerontologist 812 (2005).

similar preferences and thus allowing her own preferences to guide the decision.¹⁵⁷ 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.¹⁵⁸

Fourth, surrogates may base their decisions on factors external to the patient.¹⁵⁹ They may have "dubious motives" in that they are looking out for their own interests rather than the patient's interests.¹⁶⁰ Some surrogates make decisions to avoid the guilt from making the decision or to avoid criticism from other family members as having made the decision.¹⁶¹ Other surrogates make deliberately and intentionally selfish decisions.¹⁶²

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. Today, the balance has been struck in favor of quick and easy identification. 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." 164

¹⁵⁷ Sara M. Moorman et al., *Do Older Adults Know their Spouses' End-of-Life Treatment Preferences?* 31 RESEARCH ON AGING 463, 466-67, 482 (2009).

¹⁵⁹ 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 gametic material where there is no evidence that the patient planned to procreate. While sometimes permissible, such decisions are presumptively disallowed. *Cf.* Fine 2007, *supra* note ___, at 1558 ("never use a patient as a means to the family's end").

Interventions, 17 J. L. Med. & Ethics 74 (1999); Bernat, supra note ___, 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 where 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."); Muriel Gillick & T. Fried, The Limits of Proxy Decision Making: Undertreatment, 4 Cambridge Q. Healthcare Ethics 172 (1995); John Hardwig, The Problem of Proxies with Interests of their Own: toward a Better Theory of Proxy Decisions, 4 J. Clinical Ethics 20 (1993); J.A. McClung, Time and Language in Bioethics when Patient and Proxy Appear to Disagree, 6 J. Clinical Ethics 39 (1995); Olick & Armstrong, supra note __ ("Some may find following the patient's wishes contrary to the dictates of personal morality or conscience."); J. Spike & J. Greenlaw, Ethics Consultation: Refusal of Beneficial Treatment by a Surrogate Decision Maker, 23 J. L. Med. & Ethics 202 (1995); P.B. Terry et al., End-of-Life Decision Making: When Patients and Surrogates Disagree, 10 J. Clinical Ethics 286 (1990)

¹⁶¹ UroStream Blog, *A Tale of Two Patients* (Nov. 10, 2007), http://urostream.blogspot.com/2007/11/tale-of-two-patients.html ("[N]obody wants to be accused [of] 'killing off' grandma or grandpa.")

¹⁶² See Olick & Armstrong, supra note ___, ("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, POWER OF ATTORNEY ABUSE: WHAT STATES CAN DO ABOUT IT 4-5 (AARP 2008); see also notes __ to __, infra.

¹⁶³ Cf. Karna Halverson, Voluntary Admission and Treatment of Incompetent Persons with a Mental Illness, 32 WM MITCHELL L. REV. 161, 187 (2005).

¹⁶⁴ PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOEMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FORGO LIFE-SUSTAINING TREATMENT 147 (1983). *See also* SABATINO, *supra* note ___, at 28 ("The judiciary has neither the resources nor the expertise for taking on responsibility in all such cases.").

Still, recognizing the deficiencies of surrogate decision making, most states have various special limitations on consent by surrogates. There is perhaps no better example of the formalized distrust of surrogates than the U.S. Supreme Court's *Cruzan* decision. 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. The court was concerned that the views of a surrogate will not "necessarily be the same as that patient's would have been had she been confronted with her situation while competent."

Because they are specifically chosen by the patient herself, agents are accorded greater trust. They are often given more discretion than physician- or court-designated surrogates. For example, often only patient-selected surrogates can (a) refuse life-sustaining treatment even when the patient is not in a "terminal condition" or "permanently unconscious," (b) refuse artificial nutrition and hydration, 171 or (c) in New York, refuse life-sustaining interventions other than CPR. 172

But most surrogates are not patient-designated. And *Cruzan* is hardly the only example if 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. Had the patient been in a persistent vegetative state instead of a minimally conscious state, the wife would have had that authority. This illustrates a general inverse correlation rule: the better off the patient, the narrower the scope of surrogate authority.

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 preventing wrongful surrogate consent to *continuing* treatment only in accordance with patient wishes or best interests.

168 *Id.* at __. [run as search term]

¹⁶⁵ See SABATINO, supra note ___, at 28-29; Abigail Petersen, Survey of State's Health Care Decision-Making Standards, 28 BIFOCAL 59 (April 2007). In 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." A.M. v. Benes, 1999 CanLII 3807 (Ont. C.A.).

¹⁶⁶Cruzan v. Director, Missouri Dept. Health, 497 U.S. 261 (1990).

¹⁶⁷ *Id.* at 279-80.

¹⁶⁹ See, e.g., S.I. v. R.S., 877 N.Y.S.2d 860 (Nassau County Sup. Cy., NY 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 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.

¹⁷⁰ See, e.g., Alaska Stat. § 13.52.030; Del. Code Ann. tit. 16, § 2507; 755 Ill. Cons. Stat. §§ 40/1 to 40/65; La. Rev. Stat. Ann. § 40:1299.58.1 to .10; Me. Rev. Stat. Ann tit. 18-A, §§ 5-801 to 5-817; N.C. Gen. Stat. § 90-322.

¹⁷¹ See, e.g., Ariz. Rev. Stat. Ann. § 36-3231; Ky. Rev. Stat. § 311.631; Ohio Rev. Code Ann. § 2133.08

¹⁷² See Thaddeus Mason Pope, Legal Briefing: Advance Care Planning, 20 J. CLINICAL ETHICS 362 (2009).

¹⁷³ Wendland v. Wendland, 28 P.3d 151 (Cal. 2001).

¹⁷⁴ Cf. In re Conroy, 486 A.2d 1209 (N.J. 1985).

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 standards have problems of their own. Surrogates, after all, are still more accurate than physicians. 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 of 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. ¹⁷⁷

B. Rationale for Surrogate Replacement

Surrogates are generally obligated to make health care decisions in accordance with the patient's preferences and best interests. Particularly for a conscious or semiconscious 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. ¹⁷⁹

¹⁷⁵ See Linus Brostrom & Mats Johansson, A Virtue-Ethical Approach of Substituted Judgment, ETHICS & MED.

¹⁷⁶ See, e.g., K.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 (2001); Seckler et al., supra note __; Uhlmann et al., supra note __. 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. See Robert A. Peralman & Robert F. Uhlmann, Quality of Life in Chronic Diseases: Perceptions of Elderly Patients, 43 J. GERONTOLOGY M25 (1988). 177 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 physician's recommendation might be thought to have 'questionable motives.'"). California Law Review Commission, Study L-4003: Second Supplement to Memorandum 99-82 (Nov. 29, 1999). In one study, 13% of physicians reported that they and the surrogate disagreed "about the right thing to do." Torke et al., supra note __, at 1026. 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 tit. 16 § 2508(d)(1). This limits the scope of the physician to simply select a surrogate who agrees with the physician's recommendation. Stan Ulrich, California Law Review Commission, Staff Memorandum 96-63: Health Care Decisions: Comments on Tentative Recommendation 4 (Sept. 18, 1998).

^{178.} See generally THE RIGHT TO DIE, supra note 2, at §§ 4.01-4.10 (discussing incompetent patients and surrogacy); VETERANS HEALTH ADMINISTRATION HANDBOOK §§ 1004.01 & 14(b)(1)(c) (Aug. 14, 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 IntegratedEthics program officer or Regional Counsel"). Cf. In re Orshansky, 804 A.2d 1077 (D.C. 2002).

¹⁷⁹ See generally 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, 885 (1996) ("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."); Bernard Lo et al., Sounding Board: The Wendland Case, 346 New Eng. J. Med. 1489, 1491-92 (2002) ("The assumption that the spouse should be the surrogate

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 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. 180

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." ¹⁸¹

For example, surrogate selection was major issue in the Schiavo cases. Michael Schiavo was the surrogate for his wife Terri. He instructed providers to remove her feeding tube because Terri would have not wanted to remain in a persistent vegetative state. 182 Terri's parents challenged Michael and argued that he was an unfit surrogate. However, they also indicated that they would insist Terri be given treatment even if she had provided clear directives otherwise. 183 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." 184

Many state statutes specifically provide for surrogate replacement. Massachusetts, for example, provides that a "health care provider . . . may 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 [decision-making] standards." Florida similarly permits a provider to seek "an expedited judicial intervention" if the provider believes the surrogate's decision is not in

decision maker can be overturned - for example, if the couple has been 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 judgment, 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."). ¹⁸⁰ CODE OF MEDICAL ETHICS, *supra* note ___ § 2.20.

^{181.} Causey v. St. Francis Med. Ctr., 719 So. 2d 1072, 1076 (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.").

² In re Schiavo, (Feb. 22, 2001) ("Her statements to her friends and family about the dying process were few and they were oral.").

¹⁸³ Florida Governor Executive Order 03-201 (Oct. 21, 2003).

¹⁸⁴ C. Christopher Hook & Paul S. Mueller, The Terri Schiavo Saga: The Making of a Tragedy and Lessons Learned, 80 MAYO CLINIC PROC. 1449, 1455 (2005).

^{185 [}cite with parenthetical]

¹⁸⁶ Mass. Gen. Laws ch. 201D § 17; Cal. Prob. Code § 2992.

accord with the patient's known desires or best interests. 187

While other states provide no special judicial mechanism with which to replace surrogates, they do clearly and firmly state that surrogates acting inconsistent 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 healthcare decisions for the patient made by a person then authorized to make healthcare decisions for the patient to the extent the agent or surrogate is permitted." ¹⁸⁸

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." 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. After all, being a surrogate is not an easy job. 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?" The surrogate said she that would discuss it with her husband and call back. The surrogate soon decided to send her aunt to the hospital. 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." 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."

In another recent account, the physician explained to the surrogate that her "father's heart is weak, his kidneys are failing, and his lungs are filling with fluid." The physician then asked, "Does your father want us to employ extreme measures . . .?" ¹⁹⁵ The surrogate was conflicted. She wanted to "stop the insane cycle of hospitalizations

¹⁸⁷ Fla. Stat. §§ 765.105(1) & 765.205(1)(b).

¹⁸⁸ Del. Code tit. 16 § 2508(d)(2).

¹⁸⁹ Rowland, *supra* note ___, at 353.

¹⁹⁰ See Franz-Joself Illhardt, Conflict between a Family and the Medical Team, 19 HEC 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 ___, at 76 (explaining that most surrogates initially opposed to stopping LSMT "ultimately agree to its termination"); Pope & Waldman, supra note ___.

¹⁹¹ See, e.g., His Last Wish: Carrying Out End-of-Life Requests Not a Simple Matter, Fosters.com (Feb. 1, 2009).

¹⁹² Louise Szabo, *My Aunt's Life Was in My Hands*, GLOBE & MAIL, Jan. 21, 2010.

¹⁹³ *Id*.

Alicia von Stamwitz, An Ill Father, a Life-or-Death Decision, N.Y. TIMES, Jan. 26, 2010.
 Id.

and heroic life-saving treatments" that were not helping her father: "He is dying. And I am exhausted I want my life back." The surrogate was "acutely tempted to answer [no]."196 But she instead gave the physician the answer that she knew to be true, even though both she and the physician think it unreasonable.

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 clarify the situation. ¹⁹⁷ Specifically, they should advise the surrogate of the "duties of a good surrogate decision maker." 198 The treating physician should make sure that the surrogate understands the prognostic information about the patient. 199

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."²⁰⁰

Usually, conflict will "dissipate when communication improves, misunderstandings are corrected, and emotional and spiritual needs are met." While surrogate replacement may be an option for some intractable disputes, most futility disputes will not become intractable. Therefore, it will often be best to delay treatment decisions while the surrogate comes to terms with the patient's illness.²⁰²

¹⁹⁷ See, e.g., David E. Weissman et al., Helping Surrogates Make Decisions, FAST FACTS AND CONCEPTS 226 (Feb. 2010), available at http://www.eperc.mcw.edu/fastfact/ff_226.htm.

¹⁹⁸ See Braun et al., supra note __, 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."); CODE OF MEDICAL ETHICS, supra note __ § 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 (Jan. 30, 2009). ("First, stop asking, 'What do you want us to do?" And instead ask, 'What would (the patient's name) want us to [do]?' ... Second, you need to educate the family about their role as the decision maker. .."); Meth, supra note ___, at 2076 (recommending "education of SDM's legal obligations"); Kathryn J. Rowland et al., Surgical Futility: 'Aggressive' Surgery on the Severely Demented, 145 SURGERY 351, 352 (2009) (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. UK Guidance ¶ 109 (make clear their role is just to advise on patient wishes, views, beliefs).

¹⁹⁹ See Latifat Apatira et al., Hope, Truth, and Preparing for Death: Perspectives of Surrogate Decision Makers, 149

Annals Internal Med. 861 (2008).

200 Code of Medical Ethics, *supra* note __ § 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

²⁰¹ Mark D. Siegel, *End-of-Life Decision Making in the ICU*, 30 CLINICS CHEST MEDICINE 181, 186-88 (2009). Of course, delaying too long will undermine the patient's autonomy and/or best interests.

²⁰² Alexia M. Torke, *The Physician-Surrogate Relationship*, 167 ARCHIVES INTERNAL MED. 1117, 1120 (2007).

IV. JUDICIAL REPLACEMENT OF UNFAITHFUL SURROGATES

For the small but significant subset of cases in which intramural and informal dispute resolution mechanisms fail, surrogate selection may be an option. Indeed, it may be a legal obligation. So, why is it so underutilized?²⁰³

The main obstacle to wider acceptance of surrogate selection has not been doubt of its appropriateness but rather of its efficacy.²⁰⁴ The standard operating procedures 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."²⁰⁵

In one recent study, 17% 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 would follow the family's wishes and not the living will. 206 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."207

But the available legal precedent suggests that this reluctance to seek judicial surrogate replacement is unwarranted.²⁰⁸ Admittedly, in early futility cases, courts were generally unwilling to negate a surrogate's right to make health care decisions on behalf of a

²⁰³ Some providers recognize it as an option. See, e.g., Tayyab Ali, New Eng. J. Med comment 989CB6 ("I wish we had a committee . . . who can make binding judgments in these situations to override unrealistic choices by surrogate decision makers."); New Eng. J. Med. comments 2C4E40, 2BEE1A, 7EADFD, 73E8B7, B3A7F9, B6D5C7, E67980, F60013, FEB52C (2009).

²⁰⁴ See Meth, supra note __, 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 'err on the side of caution by continuing lifesustaining interventions, even if treatment is believed to be against the patient's wishes."); Thaddeus Mason Pope, Involuntary Passive Euthanasia in U.S. Courts: Reassessing the Judicial Treatment of Medical Futility Cases, 9 MARQUETTE ELDER'S ADVISOR 229 (2008).

²⁰⁵ Meisel & Jennings, supra note ___, at 73. In the New England Journal of Medicine poll, many respondents admitted that they would cave tocave-in to the unfaithful son's demands because of legal concerns. NEW ENG. J. MED. comments 0BD721, 1A5AFB, 1B74D5, 26011A, 2FA81B, 3511BB, 46A11C, BA8A19, BD9498, C583F1, CEC05A, E67980, F61FDB, FF6D0D. See also Kritek 2009, supra note ___ (reporting that many respondents "believed they were limited by legal concerns").

²⁰⁶ Dan M. Westphal, End-of-Life Decision Making in the Intensive Care Unit: Physician and Nurse Perspectives, 24 AM. J. MED. QUALITY 222, 225 (2009) (reporting that 72% of physicians but 91% of nurses would follow the living will); see also id. at 226 (reporting that the "main reason" physicians would follow family wishes that "clearly went against the patient's living will" was "fear of litigation"); Berger et al., supra note ___, at 49 ("Despite substantial evidence of surrogate inaccuracy . . . many physicians do not require surrogates to adhere to patient's known wishes and physicians often treat incapacitated persons contrary to expresses preferences."); BERNAT, supra note ___, 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."); 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 __ (2009) (finding only 40% of surveyed physicians believed that they had a "duty to overrule" a surrogate's wrong decision).

207 Meisel & Jennings, *supra* note ___, at 73.

See JAMES L. BERNAT, ETHICAL ISSUES IN NEUROLOGY 83 (3d ed. 2008) ("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 judgment"); Lo et al., supra note ___, at 1492 (arguing that physicians "should

accept a degree of legal uncertainty in order to do what it ethically and clinically appropriate").

patient.²⁰⁹ But in more recent cases, providers have repeatedly successfully replaced surrogates who demanded LSMT that providers deemed inappropriate.²¹⁰

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

In re Wanglie is one of the earliest and most widely-discussed medical futility cases.²¹¹ 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.²¹² Her providers determined that she could never appreciate any benefit from continued LSMT, so they advised her husband Oliver to remove the ventilator.²¹³ However, Oliver would not consent to stopping LSMT.²¹⁴

The providers petitioned the local probate court to appoint a professional conservator to make health care decisions for Helga. The hospital-nominated conservator presumably would accede to the providers' recommendation to stop LSMT, unlike Oliver. Despite the provider's efforts, the probate court denied the petition and instead appointed Oliver as conservator. The court noted that Oliver was Helga's husband of fifty-three years. Moreover, his decision to continue LSMT did not constitute grounds to remove his decision-making authority. The court could not conclude that Oliver's decision to continue LSMT was inconsistent with Helga's preferences or best interests. Preferences or best interests.

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. 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. Similarly, a

^{209.} See Cantor 1996, supra note ___, 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 ___, at 487; RIGHT TO DIE, supra note ___ § 3.16[b][3] (observing that few cases have addressed the issue of the appropriate person to serve as judicially appointed guardian)..

²¹⁰ 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 ___.

^{211.} *In re* Wanglie, No. PX-91-283 (Minn. Prob. Ct. Hennepin County June 28, 1991), *reprinted in* 7 ISSUES L. & MED. 369 (1991).

^{212.} Id. at 374.

^{213.} Id. at 371.

^{214.} *Id*.

^{215.} Id. at 371, 376.

^{216.} Id. at 372, 377.

^{217.} Id. at 376.

^{218.} Id.

^{219.} *In re* Doe, Civ. No. D-93064 (Ga. Super. Ct. Oct. 17, 1991) (mem.), *aff'd*, 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. 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.

^{220.} Nguyen v. Sacred Heart Medical Center, 987 P.2d 636, 638 (Wash. Ct. App. 1999); John Altomare & Mark Bolde, Nguyen v. Sacred Heart Medical Center, 11 ISSUES L. & MED. 199, 200 (1995) (noting that while the hospital

District of Columbia court refused to replace a mother as surrogate decision-maker for her critically ill two-month-old baby simply because she requested continued LSMT.²²¹

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."²²² But it appears that these early decisions have little relevance today.²²³

Emboldened by empirical evidence attacking the accuracy of surrogate decisions, ²²⁴ 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.

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 directive in good faith in light of available information and circumstances. 225 But where 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*. ²²⁶ 97-year-old Dorothy Livadas was in a persistent vegetative state and dependent on a PEG tube and a ventilator. Her daughter and healthcare agent, Ianthe, wanted health care providers to continue this treatment because her mother was "not done." But health care providers

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").

^{221.} Benjamin Weiser, A Question of Letting Go: Child's Trauma Drives Doctors to Reexamine Ethical Role: The Case of Baby Rena, WASH. POST, July 14, 1991, at A1.

^{222.} Burns & Truog, *supra* note ___, at 1989.

233 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. THE RIGHT TO DIE, supra note 2, § 13.03[A], at 13-13. Providers can also seek ex ante permission or ex post forgiveness for unilaterally refusing a surrogate's request. Providers can seek declaratory relief. Or providers can proceed to withdraw LSMT and defend any subsequent damages case. See Pope 2007, supra note ___; Pope 2009, supra note ___.

See supra notes to and accompanying text.

In re Drabic, 200 Cal. App. 3d at 200 (the court should confine its involvement to ensuring that surrogate has made a "good faith" decision relying on medical advice).

²²⁶ In re Livadas, No. 080370/30 (Monroe Cty., NY Supr. Ct. Apr. 28, 2008); G. Craig, Court Denies Extension of Stay in Livadas Case, DEMOCRAT AND CHRONICLE (20 August 2008).

did not think that was the right decision for Livadas. In April 2008, a New York trial court appointed Catholic Family Center as Livadas' guardian, a decision later affirmed by the appellate division. The court replaced Ianthe 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."²²⁷

In *Cardoza v. USC University Hospital*, the California Court of Appeal did not replace a surrogate but indicated that there are clear limits to the scope of an surrogate's authority. Healthcare providers complied with decisions of an appointed health care agent to continue aggressive interventions for his mother.²²⁸ But the agent's sister (and patient's daughter) brought a lawsuit alleging that providers failed to comply with her mother's advance directive. 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." Therefore, the court held that the hospital was not entitled to immunity. The hospital, the court implied, should have replaced the surrogate.

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. 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. Courts are prepared to override even well-intentioned surrogates whose demands for continued LSMT cause a patient unwarranted or extreme suffering. ²³⁰

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.²³¹ In granting the hospital's petition, the court explained that since the agent was "in denial" about his mother's deterioration and distrustful of her providers, he had not given "full consideration of acceptable medical

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²²⁷ A few weeks after its appointment, CFC, the new guardian, authorized the removal of Livadas' life support. J. Wang, *Woman at Center of Legal Battle about End-of-Life Wishes Dies*, DEMOCRAT AND CHRONICLE (29 August 2008). 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. Ianthe 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. 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 Ianthe could not bear the heavy burden of rebutting this presumption.

²²⁸ Cardoza v. USC University Hosp., No. B195092 (Cal. Ct. App. Aug. 13, 2008).

²²⁹ Cf. Cantor 1996, supra note ___, at n16 (observing that the easier sort of case is where the "patient had, while previously competent, issued instructions rejecting life support in the circumstances now at hand").

^{230.} *Cf. In re* Guardianship of Myers, 610 N.E.2d 663, 671 (Ohio Misc. 1993) (appointing guardian other than parents of permanently comatose minor where one parent refused to consent to stopping LSMT).

^{231.} In re Mason, 669 N.E.2d 1081, 1085 (Mass. App. Ct. 1996).

alternatives."232

Similarly, in the case of Gary Harvey, the court replaced the patient's wife as surrogate because she failed to follow medical advice. In January 2006, Gary Harvey fell down his basement stairs, leaving him in a persistent vegetative state. Providers soon determined that Harvey was suffering and had little to no chance of recovery. While his wife, Sara, was initially appointed guardian, she "showed a pattern of dangerous behavior."233 So, in February 2007, a court replaced Sara because she "failed to use good judgment and follow medical advice." The new guardian, Chemung County, NY 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.²³⁵

In a case referred to as Baby Terry, the court replaced the parents of two-month-old Terry Achtabowski Jr. with a guardian. 236 Baby Terry was born premature at twentythree weeks gestation, was dependent on a ventilator, and had a host of serious medical problems that made his prognosis very bleak.²³⁷ Since continued treatment was painful and offered virtually no prospect for recovery, the Genesee County Department of Social Services alleged that Baby Terry's parents were neglectful in requesting continued treatment. 238 The Michigan Probate Court did not find the parents neglectful, but it did determine that they were "incompetent" to decide what was best for their son. 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.²³⁹

In In re Howe, the Massachusetts Probate Court initially seemed to return to the earlier hostile approach to surrogate selection. The court ruled that where a surrogate decisionmaker 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."240 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. Several months later, the court suggested that the surrogate's own

^{232.} *Id.*²³³ Scott Cook & Ted Fioraliso, *Gary Harvey's Daughter Speaks Out*, WENY-TV, Dec. 16, 2009.

²³⁴ John Zick, *Man's Life in Court's Hands*, CORNING LEADER, June 22, 2009 ("Sara Harvey says her husband is a fighter who would not want to give up. . . . 'They think that I'm in denial.'"); Ray Finger, Wife Seeks Rights to Comatose Husband," STAR GAZETTE, Sept. 17, 2009 ("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.").

²³⁵ 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.

^{236.} 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, 825-826 (1994) (citing In re Achtabowski, No. G93142173GD (Mich. Probate Ct. July 30, 1993)); Baby Dies, Was Focus of Battle, ORLANDO SENTINEL, Aug. 13, 1993, at A10.

^{237.} Bopp & Coleson, supra note, at 825.

^{238.} Id. at 834.

^{239.} Id. at 826, 832.

^{240.} In re Howe, No. 03-O-1255, 2004 WL 1446057, at *21 (Mass. Prob. & Fam. Ct. Mar. 22, 2004).

personal issues were "impacting her decisions" and urged the daughter to "refocus her assessment." A year later, the hospital again planned to remove LSMT, and the court denied the daughter's request for a temporary restraining order (TRO). The daughter soon agreed to withdraw LSMT "because she believed the court was prepared to rule against her."

Finally, in *Bernstein v. Superior Court*, the dispute was between two sons of a 79-year-old Alzheimer's patient.²⁴⁴ One brother, Scot, had been the conservator. But Scot had been demanding very aggressive care that offered the father no benefit but significant suffering. While healthcare providers were not a party to the dispute, they all thought that the treatments were "inappropriate" and "futile." On the basis of the providers' testimony, the other brother, Ilya, successfully replaced Scot as conservator.

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. She claimed that this is what her father would have wanted. In fact, if the father lived for three more weeks, the daughter would inherit \$10 million. If the father died sooner, another daughter from another marriage would inherit the money. Clearly, surrogates basing their treatment decisions on such selfish, non-patient-oriented reasons should be replaced. And they are.

In *In re Rochester General Hospital*, Mr. Levin was admitted to the hospital for certain medical problems experienced while a patient in a nursing home. The patient's adult son had been previously granted a health care proxy, as well as having been appointed under a power of attorney. 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. The hospital commenced a special proceeding for the appointment of guardian. The court granted the petition, explaining that it "entertain[ed] serious doubts as to [the son's] ability to make future decisions pursuant

242. See Liz Kowalczyk, Plan to Take Woman off Life Support is Halted, BOSTON GLOBE, Feb. 23, 2005, at B1.

^{241.} *Id.* at *20-21.

^{243.} Daughter Explains Agreement to End Care, BOSTON GLOBE, Mar. 23, 2005, at B2.

²⁴⁴ Bernstein v. Sup. Ct. Ventura Cty., No. B212067 (Cal. Ct. App. Feb. 2, 2009).

²⁴⁵ Critical Care (Live / Artisan 1997). Such a motive obtained more generally in 2009, because the inheritance tax was lifted for deaths in 2010. 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." Laura Saunders, *Rich Cling to Life to Beat Tax Man*, WALL ST. J., Dec. 30, 2009. 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.*

²⁴⁶ 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) ("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.").

²⁴⁷ 601 N.Y.S.2d 375 (1993).

to the health care proxy."248

Not all conflicts are financial in nature.²⁴⁹ In *In re Martin*, the mother of a patient challenged the appropriateness of the patient's wife as surrogate. 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. Such evidence would indicate that the wife was not a suitable surrogate.²⁵⁰ More starkly, in June 2009, Pedro Rosabal killed his two children, then turned the gun on himself and ended up on life support. Legal and ethical experts agreed that it would be inappropriate for Rosabal's treatment to end up in his wife's hands.²⁵¹

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

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. ²⁵⁶ In the case of Michael Arzuaga-Guevara, life 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. ²⁵⁷ Another case involved a mother who abused her

²⁴⁸ *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 (Tenn. 1998); Bryan v. Holzer, 589 So.2d 648 (Miss. 1991); *In Lawrence*, 563 So.2d 195 (Fla. App. 1990). 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, *Brooke Astor's Son Guilty in Scheme to Defraud Her*, N.Y. TIMES, Oct. 8, 2009.

²⁴⁹ See, e.g., RIGHT TO DIE, supra note __ § 3.24[c]; Stanley A. Terman, The Sooner Mother Dies, the Better" in Peaceful Transitions: An Ironclad Strategy to Die When and How YOU Want ch.5 (2009).

²⁵⁰ In re Martin, 504 N.W.2d 917, 925-926 (Mich. App. 1993). The trial court later found that there was no such evidence. 517 N.W.2d 749, 753-54 (Mich. App. 1994), *rev'd on other grounds*, 538 N.W.2d 399 (Mich. 1995).

²⁵¹ Cindy George & Paige Hewitt, Kids' Deaths Put Hospital in Ethical Quandary, Hous. CHron., June 18, 2009.

²⁵² In re Ramirez, CV2007-051579 (Maricopa Sup. Ct, Ariz. 2007) (Hauser, J.).

²⁵³ Gary Grado, Judge Orders Life Support for Chandler Hospice Patient, EAST VALLEY TRIBUNE, June 14, 2007.

²⁵⁴ Dennis Wagner, *Injured Man's Awakening Called 'Miracle*,' USA TODAY, June 27, 2007.

²⁵⁵ Gary Grado, Crash Survivor's Case Spurs New State Law, EAST VALLEY TRIBUNE, July 18, 2009.

²⁵⁶ See, e.g., J.M. Appel, Mixed Motives, Mixed Outcomes When Accused Parents Won't Agree to Withdraw Care, 35 J. MED. ETHICS 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 as Litem, 113 PEDIATRICS 141 (2004); Vanessa Miller, Boulder County Officials Discuss Injured Infant's Future, COLO. DAILY, July 29, 2009 ("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.").

²⁵⁷ In re Michael Arzuaga-Guevara, Del. Supr., No. 506, 2001, (Oct. 23, 2001) Del. Ch., CM No. 10211, (Oct. 9,

two-year-old baby. Providers recommended stopping LSMT, but the baby's father refused because he was concerned about his wife's criminal liability. 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.²⁵⁸

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 and the receipt of pension and government benefits. There is always a conflict of interest. But this, in and of itself, cannot be sufficient to establish a material conflict of interest. Otherwise, the very concept of surrogate decision-making would be swallowed by this exception. "The issue is not the existence of a conflict of interest, but its pervasiveness and its effect."

C. Ontario Capacity and Consent Board

In Ontario, the Consent and Capacity Board (the CCB) is a body created by the Ontario government under its Health Care Consent Act. "When 'in-house' conflict resolution fails, [the] CCB can mediate. If this mediation fails, [the] CCB adjudicates . . ." "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."

Of particular note is that the CCB is specially designed to ensure that substitute decision makers comply with the principles of substitute decision-making. 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. If the

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^{2001);} see also In re Nicholas Truselo, Del. Fam. Ct., No. CN00-09299 (Sept. 18, 2000) (Ableman, J.) (determining 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 Nicholas should receive comfort measures only). ²⁵⁸ Steve Twedt, Should Comatose Baby Live? Hospital, Dad Differ, PITT. POST-GAZETTE, June 3, 1990, at A1. The father then acceded to the hospital's recommendation to withdraw LSMT. Father Ends Life Support, PITT. POST-GAZETTE, June 24, 1990, at A3; Mary Pat Flaherty, Right to Die Decision Has Little Impact Here, PITT. POST-GAZETTE, June 27, 1990, at A1. Cf. J.N. v. Sup. Ct., 67 Cal. App. 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 pretermination protection order allowing DNR for minor without parental consent violated the parents' right to due process); In re Smith, 133 P.3d 924, 929-30 (Or. Ct. App. 2006) (holding 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); In re Stein, 821 N.E.2d 1008 (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 Tabatha R., 564 N.W.2d 598, 605 (Neb. 1997) (discussing due process rights of parents during termination of parental rights determination). ²⁵⁹ RIGHT TO DIE, *supra* note __ § 3.24[c].

HEALTH CARE CONSENT ACT, S.O., ch. 2 (1996) (Can.), available at

http://www.canlii.org/on/laws/sta/1996c.2sch.a/20080821/whole.html.

261 Mark Handelman & Bob Parke, *The Beneficial Role of a Judicial Process When "Everything" Is Too Much*, HEALTHCARE O., Winter 2008, at 46, 48.

²⁶² *Id.* at 50. *See also* Joaquin Zuckerberg, *End-of-Life Decisions*, *A View from Ontario and Beyond*, 16 EUR. J. HEALTH L. 139, 159 (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).

 $^{^{263}}$ These are set forth in Health Care Consent Act $\S~21.$

²⁶⁴ HEALTH CARE CONSENT ACT §§ 37(4) & 37(5).

surrogate fails to do so, then the CCB passes the right to act as surrogate to the next eligible person.²⁶⁵

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. This is basically a petition for the CCB to determine whether the SDM complied with the principles for substitute decision-making. The CCB sits in expert panels comprised of a lawyer, a psychiatrist, and a public member. 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.

Regularly, when providers recommend treatment that includes the withholding or withdrawal of life-sustaining medical treatment, the CCB directs reluctant surrogates to consent. For example, in the 2009 case of *In re N*, the 85-year-old patient was in septic shock, had numerous infections, kidney failure, and widespread skin breakdown. She was experiencing pain and was dependent on a mechanical ventilator and had almost no ability to come off it. For these reasons, N's treating physician proposed withdrawal of life support and palliative care. But N's surrogate, Mr. NP, would not consent to this plan of treatment. 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."

The CCB held that the patient had expressed "no prior capable wish that pertained to the circumstances." 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 were herself aware of those expert medical opinions." Therefore, the Board had to determine not whether the surrogate was acting in accord with the patient's wishes but whether the surrogate was acting in her best interests.

The CCB held that the surrogate was not acting in the patient's best interests. 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. And there was

²⁶⁵ HEALTH CARE CONSENT ACT § 37(6).

²⁶⁶ HEALTH CARE CONSENT ACT § 37(1). *See* In re E at 5 ("The onus is always on the health practitioner").

²⁶⁷ CONSENT AND CAPACITY BOARD, ANNUAL REPORT 2007-2008, available at

http://www.ccboard.on.ca/english/publications/documents/annualreport20072008.pdf.

²⁶⁸ Barbulow ¶¶ 25-27 (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 (ON S.C.).

²⁶⁹ See, e.g., In re E, 2009 CanLII 28625 (Ont. C.C.B.) (directing that son comply with no-CPR, no-ventilator treatment plan of his father's physician); Barbulov v. Cirone, 2009 CanLII 15889 (Ont. S.C.) (affirming CCB direction that son consent to the no-CPR, no-dialysis treatment plan proposed by his father's physician).

²⁷⁰ In re N, 2009 CanLII 42576, at 6-8 (Ont. C.C.B.).

²⁷¹ *Id.* at 1.

²⁷² *Id*.

²⁷³ *Id*.

²⁷⁴ *Id*.at 12.

²⁷⁵ *Id.* at 13.

no prospect that there would be any improvement in her condition.²⁷⁶ The Board recognized that the family held out hope, but found that "the family's hope was not at all realistic."²⁷⁷ The Board found that the surrogate was "blinded by [his] obvious love for N and could not view her situation objectively."²⁷⁸ Accordingly, the CCB directed Mr. NP to consent to the proposed treatment plan.²⁷⁹

Remarkably, the CCB has reached similar results, even in cases where the surrogate's decision has 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 anticipate the patient's current, very different circumstances.²⁸⁰

D. Queensland Guardianship and Administration Tribunal

Similar to the CCB is the Queensland Guardianship and Administration Tribunal (QGAAT).²⁸¹ The Tribunal has a multidisciplinary composition comprised of at least a lawyer and a professional with extensive knowledge or experience of persons with impaired decision-making.²⁸² If there is a "dispute about who should act as guardian" 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."²⁸³

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.²⁸⁴ But AAC's children, who were the default surrogates ("statutory

²⁷⁶ *Id.* at 15.

²⁷⁷ *Id.* at

²⁷⁸ *Id.* at 17.

²⁸⁰ See, e.g., Conway v. Jacques [2002] O.J. No. 2333 (Ont. C.A.) (affirming CCB where surrogate refused to consent to anti-psychotic medication for patient because 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 at 27-28 (finding that prior comments of patient "were not precise and lacked particularity," 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 ¶ 61 (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 a limited command of written English").

281 Victoria has a similar mechanism under its Guardianship and Administration Act 1986. If a surrogate withholds

consent to treatment and the provider thinks the surrogate is not making the right decision, the provider can provide the surrogate with a notice (Section 42M Notice) within three days of the refusal. 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. If the surrogate does nothing, the practitioner can proceed. If the surrogate makes an application, VCAT will decide whether the treatment can proceed.

Queensland Guardianship and Administration Tribunal: Annual Report 2007-2008 11-12 (Oct. 2008).
 QGAAT Annual Report at 17, 21.

²⁸⁴ In re AAC [2009] QGAAT 27 ¶¶ 1-4, 61. The proceeding was brought by the children to challenge the Adult Guardian's decision. The Public Guardian can withdraw LSMT where continuation is "inconsistent with good medical practice." In re SAJ [2007] QGAAT 62; In re HG [2006] QGAAT 26.

health attorneys"), refused to allow the withdrawal of life sustaining measures. So, providers requested the Adult Guardian to consent to withdrawal on the basis that the children's refusal to withdraw was "inconsistent with good medical practice." The Adult Guardian consented. The children's challenge to that decision was rejected by the Tribunal.

V. THE LIMITS OF SURROGATE SELECTION

Surrogate replacement is a statutorily- and judicially-recognized option for resolving intractable futility disputes. But practical problems in application limit its use. 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 can often establish both that the patient belonged to a certain religion and that the tenets of that religion required 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 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 the patient would have wanted made on her behalf. After all, one cannot replace a "good" surrogate.²⁸⁷

Take, for example, a recently-reported case of a 64-year-old man found to have an incurable cancer of the esophagus. Because of the patient's unawareness and his very poor prognosis, his providers believed that continued ICU care was inappropriate. But the patient's surrogate insisted that he remain in the ICU, on ventilator support and on a full code status. 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. Importantly, the surrogate further explained that "that the patient

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²⁸⁵ AAC ¶ 5

 $^{^{286}}$ AAC \P 6. This is defined in the controlling statute as "(a) the recognized medical standards, practices, and procedures of the medical profession in Australia; and (b) the recognized ethical standards of the medical profession in Australia." Schedule 2 sec 5B.

²⁸⁷ 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.). In that case, the Court found that the evidence indicated that the patient really did desire the treatment requested by her surrogate.

was also a man of deep faith who would likewise insist on this approach."²⁸⁸ It is unlikely that providers can replace this surrogate.

Indeed, religion is at the bottom of most intractable futility disputes.²⁸⁹ For example, in the widely-discussed *Golubchuk* case, physicians determined that 84-year-old Samuel Golubchuk had minimal brain function and that his chances for recovery were slim.²⁹⁰ But Golubchuk's adult children argued that taking their father off life support would be a sin under their Orthodox Jewish faith.²⁹¹ Here, as in many cases, since it was patient's religion, and not just the surrogate's religion, that compels continued treatment, it seems impossible to replace such faithful surrogates.

Surrogate selection seems inapplicable and inadequate to address the single most common type of intractable futility dispute. Furthermore, a practical reality seriously exacerbates this problem. Surrogates are a primary source of information about the patient's preferences and values. So no matter what the applicable evidentiary standard, they could "manufacture" or at least "polish" evidence to meet that standard. And the limitations do not stop there.

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

In many futility disputes it will be difficult for providers to demonstrate that surrogates demanding continued treatment are being unfaithful to patient instructions or preferences. First, since applicable instructions are rarely available, cases like *Livadas* will be rare. ²⁹⁵ 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 evidence regarding patient preferences. Again, 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.

²⁹⁰ Golubchuk v. Salvation Army Grace Gen. Hosp., 2008 MBQB 49 (2008).

manufacturing evidence. Sandra H. Johnson, *Quinlan and Cruzan: Beyond the Symbols, in* HEALTH LAW AND BIOETHICS 53, 66 (2009). Scheniderman 2007 encourage polishing.

²⁹⁵ See supra notes __ to __ and accompanying text.

²⁸⁸ Robert D. Orr, Continuing "Futile" ICU Support at Relative's Insistence, 25(3) ETHICS & MED. (2009).

²⁸⁹ See supra note __

²⁹¹ Carla Tonelli, Canadian Life-Support Case Pits Religion vs Science, WASH. POST, Dec. 14, 2007.

²⁹² The Robert Powell Center for Medical Ethics, *The Will to Live Project*,

http://www.nrlc.org/euthanasia/willtolive/index.html; *see also* Texas Right to Life, *Will to Live*, http://www.texasrighttolife.com/lifeIssues_euthanasia_will.php ("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 ").

²⁹³ Benes ¶ 44 ("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 ").
²⁹⁴ 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. [cite] Judge Teel denied that he assisted in

1. Few Advance Directives are Available and Applicable.

Notwithstanding many government and private initiatives, a majority of Americans do not complete advance directives. Furthermore, even the minority that does complete advance directives often does so in an ineffective manner. First, either the very existence or at least the location of the form is unknown at the time of treatment. Second, even if the form is available, it is often not very informative anyway. After all, "most patients cannot possibly have anticipated and discussed their preferences in the numerous specific clinical states that may later occur."296

One notable example of failed surrogate selection is In re University Hospital of the State University of New York Upstate Medical University. Providers determined that patient Yvette Casimiro's physical condition satisfied the specified criteria in her advance directive to invoke the patient's expressed wishes that the life sustaining treatment currently in place be terminated.²⁹⁷ When the surrogates refused to consent, providers went to court. 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."298

The court refused to replace the surrogate. 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. Furthermore, the court credited the surrogates' testimony concerning the patient's "strongly expressed religious beliefs concerning who can take a life."²⁹⁹ 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, to too will it 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 point of laws that gave them rights by status.³⁰⁰

²⁹⁶ BERNAT, *supra* note ___, 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 Peterson, Patient-Centered Informed Consent in Surgical Practice, 141 ARCHIVES SURGERY 86 (2006); A. Sehgal et al., How Strictly Do Dialysis Patients Want their Advance Directives Followed? 267 JAMA 59 (1992). 754 N.Y.S.2d 153 (2002).

²⁹⁸ *Id.* at 154.

³⁰⁰ 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. 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 (2002).

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 97-year-old Hazel Wagner to be taken off a ventilator and have her feeding tube removed.³⁰¹ 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 unethical to keep her alive in her current condition. 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. For this reason, the judge denied Dr. Drozdowski's request and deferred to the surrogate's decision to continue treatment.

3. Patients Want their Surrogates to Have Discretion.

One serious obstacle to surrogate selection is that the requisite evidence to demonstrate surrogate unfaithfulness is often unavailable. Providers often have no substantial evidence of patient instructions or wishes with which to establish surrogate deviation. But even if there were such evidence, it might not be sufficient to demonstrate that the surrogate was a maverick. 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.³⁰² A majority of terminally ill patients would prefer the decision of their surrogate even if it flatly contradicted explicit instructions in their living will.³⁰³

While such flexibility does leave more room for error, it is a recognized advantage of surrogates over advance directives. 304 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.³⁰⁵

³⁰¹ Bonnie Booth, Doctor's Request to End Patient's Care Denied, Am. MED. NEWS, June 12, 2006.

³⁰² Jeffrey T. Berger, When Surrogates' Responsibilities and Religious Concerns Intersect, 18 J. CLINICAL ETHICS 391, 391 (2007). See also N.A. Hawkins et al., Micromanaging Death: Process Preferences, Values, and Goals in End-of-Life Medical Decision Making, 45 GERONTOLOGIST 107 (2005); Perkins, supra note __; A. Sehgal et al., How Strictly Do Dialysis Patients Want their Advance Directives Followed? 267 JAMA 59 (1992); Jeffrey T. Berger et al., Surrogate Decision Making: Reconciling Ethical Theory and Clinical Practice, 149 Annals Internal Med. 48, 48 (2008) ("[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"); C.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 (2000).

³⁰³ P.B. Terry et al., End-of-Life Decision Making: When Patients and Surrogates Disagree, 10 J. CLINICAL ETHICS 286 (1999).

³⁰⁴ [cite]

³⁰⁵ See supra notes __ to __ and accompanying text.

surrogates will often lack sufficient evidence to establish that the patient wanted them to have this discretion.

C. Silver Lining: Best Interests

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, 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. Take, for example, the case of Mary Grover. Mary suffered a brainstem stroke leaving her quadriplegic, dependent on a ventilator, and with diminished mental function. Her healthcare providers proposed that the focus of Mary's care be comfort only. But Marjorie Grover, Mary's surrogate and the oldest of her ten children, would not consent. MG correctly noted that at G's recent nursing home review, G's wish was to receive "full resuscitation measures." The providers are in as good (or perhaps better) position as good (or perhaps better) as good (or perhaps better) are in as good (or perhaps better) and good (or perhaps better) as good (or perhaps better)

But the CCB still replaced MG as surrogate. The Board noted that "prior capable wishes are not to be applied mechanically or literally." There was no evidence that Mary had her current circumstances in mind or that her wishes were applicable to those circumstances. MG's evidence of Mary's values was "quite vague" 11

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 that G's other nine children all agreed with the proposed treatment plan³¹² and (2) that life-sustaining treatments would cause infections and hospitalizations but neither "improve the overall quality of G's life not lessen the disability.³¹³ The Board disregarded MG's decision, finding that she was basing it on "hope" rather than "experienced medical opinions"³¹⁴

³⁰⁶ *Cf.* Braun et al., *supra* note ___, at 252 (since surrogates are only "reporters" under the subjective and substituted judgment standards, only under the best interest standard do surrogates engage in "genuine decision making"). Surrogates are regularly overruled on an application of the best interest standard. *See*, *e.g.*, In re Storar, 420 N.E.2d 64 (N.Y. 1981).

³⁰⁷ In re G, 2009 CanLII 25289 (ON C.C.B.); *aff'd*, In re Grover, 2009 CanLII 16577 (ON S.C.).

³⁰⁸ *Id.* at 9.

 $^{^{309}}$ *Id* at 15.

³¹⁰ *Id.* at 27.

³¹¹ *Id.* at 29.

³¹² *Id.* at 29.

 $^{^{313}}$ *Id.* at 31.

³¹⁴ *Id.* at 31. The Board also observed that MG may have been biased because she was "working her life plans around her mother." *Id.*

CONCLUSION

Professor Truog is right to endorse surrogate selection as a solution to intractable futility disputes. It is a mechanism that can often 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. In short, Truog is right to oppose the empowerment of intramural healthcare ethics committees to adjudicate futility disputes. But he too quickly dismisses proposals for more legitimate, more independent ethics committees. ³¹⁵

³¹⁵ Truog 2007, *supra* note __, at 2; Truog 2007, *supra* note __, at 1559.