April, 2007

Medical Futility, Patient Autonomy, and Professional Integrity: Finding the Appropriate Balance

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I. Introduction

The question of who has the authority to make the final decision regarding withholding or withdrawing life-sustaining medical treatment has been the subject of debate for more than a generation.1 This often emotional question over “pulling the plug” has prompted scholarly discourses, legal opinions, and popular media portrayals.2 The initial debate focused on patient autonomy and patients refusing unwanted treatment. The more recent debate has focused on the other end of the spectrum where the patient or surrogate decision-maker is demanding treatments that the health care team believes to be futile or medically inappropriate.3

1 See generally Norman L. Cantor, Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying, 29 J.L. MED. & ETHICS 182.

2 See WHO’S LIFE IS IT ANYWAY? (Metro-Goldwyn-Mayer 1981); see also In re Quinlan, 355 A.2d 647, 671 (1976)(holding that a comatose woman could be removed from the ventilator that was breathing for her); see also Cruzan v. Director, 497 U.S. 261, 304 (1990)(noting that competent patients would have a liberty interest in refusing unwanted medical interventions).

3 See Amir Halevy and Amy L. McGuire, The History, Successes and Controversies of the Texas “Futility” Policy, 43-Jun HOUS. LAW.
The arguments over withholding and withdrawing life-sustaining therapy have evolved over time as the typical end-of-life scenarios have changed. Starting with the 1970’s, the classic case involved a dying or severely brain-damaged patient whose family members requested discontinuation of life-sustaining medical treatment; an illustrative case is that of Karen Ann Quinlan, a young woman who lapsed into a coma after consuming a combination of alcohol and drugs. Society and the courts grappled with the question of whether patients or their surrogates could refuse medical treatment recommended by the health care team. Was such a refusal the right of the patient? Was it assisting suicide? Was it even murder? When presented

38, 39 (2006)(noting that the early cases “provided a framework for resolving conflicts at one end of the spectrum, situations where the physician recommended unwanted medical treatment, but did nothing for the other end of the spectrum, situations where the patient or family demanded medical interventions that the physicians thought were medically inappropriate or futile.”)

See Quinlan, 355 A.2d 647 (N.J. 1976)(ruling on the first “right to die” case to go to court).

California charged two doctors with murder and conspiracy to commit murder after withdrawing life-sustaining therapy from a severely brain-damaged patient at the request of the patient’s
with such cases involving physician-driven overtreatment\(^6\), courts consistently held that a competent patient had a right to refuse unwanted medical therapy.\(^7\) Moreover, the courts concluded that

\[\text{family; charges were eventually dismissed. See Barber v. Superior Court, 147 Cal. App. 3d 1006, 1022 (Cal.App.2.Dist. 1983) (holding that “the petitioners’ omission to continue treatment under the circumstances, though intentional and with knowledge that the patient would die, was not an unlawful failure to perform a legal duty”).} \]

\(^6\) Physician-driven overtreatment, for the purposes of this Article, is defined at medical treatment provided to a patient at the insistence of the health care team in spite of the patient, or the patient’s surrogate decision maker, requesting that the intervention be withheld or withdrawn. Patient-driven overtreatment, for the purposes of this Article, is defined as medical treatment provided at the insistence of the patient, or surrogate decision-maker, in spite of the health care team’s belief that the treatment is medically inappropriate or futile.

\(^7\) See Quinlan, 355 A.2d at 663 (holding that a competent patient would have a privacy interest in refusing unwanted medical treatment); see also Cruzan, 497 U.S. at 279 (assuming that a competent patient would have a liberty interest in refusing unwanted medical treatment).
the appropriate surrogate decision-maker could refuse such therapy on behalf of an incompetent patient in certain circumstances.\textsuperscript{8}

By the late 1980s, however, commentators were beginning to discuss potential problems at the other end of the treatment spectrum.\textsuperscript{9} A growing consensus emerged that life-sustaining interventions were not always appropriate for all patients. For example, the National Conference on Cardiopulmonary Resuscitation and Emergency Cardiac Care, the group responsible for developing the national guidelines for cardiopulmonary resuscitation (CPR), recommended that CPR should be used only to

\textsuperscript{8} Id.

\textsuperscript{9} See Leslie Blackhall, Must We Always Use CPR? 317 \textit{New Eng. J. Med.} 1281, 1283 (1987)(arguing that CPR was not always appropriate and that it’s utilization should depend on the patient’s overall clinical condition); see also Alan Brett and Lawrence McCullough, \textit{When Patients Request Specific Interventions: Defining the Limits of Physician Obligation}, 315 \textit{New Eng. J. Med.} 1347, 1349 (1986)(suggesting that physicians did not have an obligation to provide whatever interventions or treatments a patient requested and that there had to be a “modicum of benefit” to justify providing the desired interventions).
attempt resuscitation for a patient whose death was not unexpected.\textsuperscript{10} If the patient has a right to refuse unwanted treatment, does the patient have the right to receive medical treatments that the treating physicians and health care team believes are not medically appropriate? The representative case was no longer the dying patient kept alive by the demands of the medical professionals but the dying patient kept alive by the demands of the family or surrogate decision-makers.\textsuperscript{11} By the

\textsuperscript{10} See American Heart Association, Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiac Care, 268 J. AM. MED. ASS’N 2171, 2183 (1992) (providing an example of “futile” CPR as when “[no] survivors after CPR have been reported under the given circumstances in well-designed studies. For example, when CPR has been attempted with metastatic cancer, several large series have reported that no patient survived to hospital discharge.”)

\textsuperscript{11} See Amir Halevy and Baruch Brody for the City-Wide Taskforce on Medical Futility, A Multi-institution Collaborative Policy on Medical Futility, 276 J. AM. MED. ASS’N 571 (1996) (providing examples of cases including an infant born with multiple congenital abnormalities that rendered survival unprecedented and whose parents sequentially demanded amputations of several gangrenous limbs, in spite of opposition from the medical care
early 1990s, debate in the medical and biomedical ethics literature raged regarding the definition and the utility of the medical futility concept.\textsuperscript{12} Several cases, discussed in detail in team, in an attempt to "do everything," and including the case of a comatose woman dying of multisystem organ failure whose surrogate decision-maker, her estranged husband demanded that the medical staff "do everything to my wife", in spite of numerous conferences with the medical staff recommending comfort care only.)

\textsuperscript{12} See Larry Schneiderman et al., \textit{Medical Futility: Its Meaning and Ethical Implications,} 112 \textit{ANNALS INTERNAL MED.} 949 (1990)(offering two potential definitions of futility, one quantitative of "when physicians conclude . . . that in the last 100 cases a medical treatment has been useless, they should regard that treatment as futile" and one qualitative of "[i]f a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive medical care, the treatment should be considered futile"); see also Robert Truog et al., \textit{The Problem with Futility,} 326 \textit{NEW ENG. J. MED.} 1560 (1992) (arguing that the concept of futility is an unworkable concept and inappropriate as a basis to make decisions regarding end-of-life treatment); see also Baruch Brody and Amir Halevy, \textit{Is Futility a Futile Concept?} 20 \textit{J. MED. \& PHILOSOPHY} 123 (1995)(critiquing
Section III, were litigated with varying results. In 1996, the American Medical Association recognized that the “difficulties of defining futility are balanced with the need to have an operational understanding of it.” The AMA recommended that various definitions of medical futility in the medical literature and concluding that it could not be meaningfully defined in a substantive way).

13 See In re Helga Wanglie, Fourth Judicial District (District Court Probate Court Division) PX-91-238, Minnesota, Hennepin County (1991) (holding that Ms. Wanglie’s husband was the appropriate decisionmaker and that the hospital could not be appointed her guardian); see also In the matter of Baby K, 16 F.3d 590 (4th Cir. 1994) (holding that not providing resuscitative treatment to an anencephalic infant would violate the federal Emergency Medical Treatment and Active Labor Act); c.f. Gilgum v. Mass. Gen. Hosp., Superior Ct. Civ. Action No. 92-4820 Suffolk Co., Mass., verdict April 21, 1995 (jury finding that physicians’ professional autonomy was an appropriate basis for withholding resuscitation from a dying elderly woman and that there was no liability despite patient’s death).

14 Council on Ethical and Judicial Affairs, American Medical Association, Medical Futility in End of Life Care, Report 2-I-96.
hospitals adopt a “fair process approach for determining, and subsequently withholding or withdrawing, what is felt to be futile care.” 15 In Texas, the Legislature passed the Advance Directives Act in 1997 which included a provision that created a process-based mechanism for a physician “who refuses to honor a patient’s advance directive or a health care or treatment decision made by or on behalf of a patient.” 16 Several years after the act’s passage, two highly publicized cases 17 have


focused attention on the act’s futility provision and have resulted in calls for the act’s reform or abolition.\textsuperscript{18}

The first part of this Article reviews the history of patient refusals of unwanted therapies and the establishment of the patient’s right to refuse such treatments. The second part analyzes the development of the concept of medical futility including developments in both the legal and medical communities. The third section considers the history of the Texas statute and its recent legal challenges. The fourth section of the Article argues that given the emotional and political turmoil created by such decisions, it is important that any process which potentially limits patient or surrogate choice be firmly grounded on an accepted and defensible ethical principle. Additionally, the Article argues that the relevant principle is that of professional integrity and that the courts should rediscover the “ethical integrity of the medical

\textsuperscript{18} See Todd Ackerman, \textit{Families Urge Change to State Futile-Care Law}, \textit{Houston Chron.}, August 10, 2006, at B1 (detailing a legislative hearing where many speakers urged significant changes in the futility provision of the Advance Directives Act).
profession”¹⁹ as a counterbalance to patient autonomy in appropriate cases. The Article concludes that it would be ironic if a country that does not provide access to appropriate health care as a fundamental right were to decide that an individual patient’s demands for inappropriate medical treatment should be granted over the objections of healthcare professionals thereby creating a right to medically inappropriate health care services.²⁰

II. Physician Driven Overtreatment and Patient Autonomy

This section of the Article reviews the history of medical decision-making. It explores the evolution of medical decision-making from a paternalistic regime where physicians made all the decisions to that of the current informed consent era where patients retained decision-making authority. The Article also analyzes the correlative concept of informed refusal and concludes with the argument that a competent patient, or his or


²⁰ See Wideman v. Shallowford Cmty. Hosp., 826 F.2d 1030, 1032 (11th Cir. 1987) (noting that “we can discern no general right, based upon either the Constitution or federal statutes, to the provision of medical treatment and services. . .”)

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her appropriate surrogate decision-maker in cases of incompetence, has an autonomy based right to refuse unwanted medical treatments.

Medical technology, medical ethics, and legal doctrine regarding informed consent and medical decision-making have advanced significantly over the past century. One of the major tensions in medical decision-making is the information disparity between the physician and the patient. The old aphorism of “the doctor knows best” has been gradually limited by various court decisions. Two medical decision-making models have been prominent over the past century, medical paternalism and patient

\footnote{See Ronald M. Epstein, Brian S. Alper, and Timothy E. Quill, \textit{Communicating Evidence for Participatory Decision Making}, 291 J. AM. MED. ASS’N 2359 (2004).}

\footnote{See John Wennberg, \textit{Improving the Medical Decision Making Process}, 7 HEALTH AFFAIRS 100 (1988) (noting that “[t]he doctor knows best: physicians, because of their formal training, continuing education, and extensive experience, are assumed to know the scientifically correct way to treat disease. Moreover, they are assumed to understand vicariously the needs and wants of patients and thus are qualified to make utility or value judgments for patients.”)}
autonomy.\textsuperscript{23} The medical paternalism model is based on the idea that the doctor knows more than the typical patient and thus knows what is best for the typical patient.\textsuperscript{24} Thus, the physician should make the medical decisions. The patient autonomy model, however, is based on the idea that physicians do not treat typical patients; rather, they take care of particular patients and the particular patient knows his values and goals and thus is in the best position to make decisions regarding his life and health.\textsuperscript{25} In both medical ethics and health law, patient autonomy has replaced medical paternalism as the dominant decision-making model.\textsuperscript{26}

The first major limit to physician authority occurred in 1914 with Schloendorff v. Society of New York Hospital\textsuperscript{27} establishing the doctrine of simple consent.\textsuperscript{28} Justice Cardozo,


\textsuperscript{24} Id.

\textsuperscript{25} Id.

\textsuperscript{26} Id.

\textsuperscript{27} 105 N.E. 92 (N.Y. 1914).

\textsuperscript{28} See Schloendorff, 105 N.E. at 93 (holding that an operation performed without the patient’s consent is an assault).
writing for the court, opined that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.”\textsuperscript{29} However, this decision did nothing to bridge the information gap between physicians who had the relevant information and the patients who now had decision-making authority. Patients had the right to give or refuse consent for medical therapies, but there existed no legal requirement that they receive information to make their decision based on known facts.

It took more than fifty years to formally bridge this information gap with a requirement for “a full disclosure of facts necessary to an informed consent.”\textsuperscript{30} In 1957, \textit{Salgo v. Leland Stanford Jr. University Board of Trustees} held that a physician was required to provide his patient with all the information necessary to make an informed decision:

\begin{flushright}
\textit{Id.}
\end{flushright}

\textsuperscript{29} \textit{Id.}

\textsuperscript{30} \textit{Salgo v. Leland Stanford Jr. Univ. Bd. of Trs, 317 P.2d 170 (Cal. App. 1957)} (introducing the term “informed consent” in reversing a medical malpractice case where the court held that the lower court had made a prejudicial error in instructing that as a matter of law, an inference of negligence had arisen).
A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment. Likewise the physician may not minimize the known dangers of a procedure or operation in order to induce his patient's consent.\textsuperscript{31}

The basic requirements for informed consent include disclosure of the patient’s disease process, the risks and the benefits of the proposed treatment, and any viable alternative therapies, including doing nothing.\textsuperscript{32}

The question remaining after \textit{Salgo} was how much information did the patient need to make an informed decision. It would be unrealistic to require the physician to teach the patient everything about the disease process, the therapeutic options, and the associated risks and benefits. Requiring all such information would be impractical in terms of both time and in terms of most patients’ lack of basic scientific knowledge. The purpose of informed consent is to allow the patient to make an informed decision, not to enroll him in a mini-medical education. Initially, many jurisdictions adopted a professional

\begin{footnotesize}
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\item \textsuperscript{31} \textit{Id.} at 181.
\item \textsuperscript{32} See \textit{Kelley’s Textbook of Internal Medicine}, 4\textsuperscript{th} Edition, (David Humes ed., Lippincott, Williams, & Wilkins 2000); \textit{see also} Tom Beauchamp and James Childress, \textit{Principles of Biomedical Ethics}, (Oxford University Press, 3\textsuperscript{rd} Ed. 1989); TEX. ADMIN. CODE, Title 25 § 601.
\end{itemize}
\end{footnotesize}
standard of information disclosure. The professional standard obligated the physician to disclose to the patient information that other physicians routinely disclosed to their patients. The problem with such a standard is that physicians in a community might choose not to provide information that the patient would consider significant. If the basis of informed consent was to empower the patient to make decisions regarding his or her care based on good information, allowing physicians to filter and ration information based on physicians’ preferences and biases would undercut the patient’s truly autonomous choice. Likewise, a pure patient-based subjective standard for informed consent, based on the idiosyncrasies of an individual patient, especially if applied with the benefit of hindsight, would be unfair to physicians.

An alternative to both the professional standard and the subjective, patient-based standard of disclosure was shaped in

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34 Id.

35 See Beauchamp and Childress, supra note ___ at 87-88.

36 Id. at 90-91.
1972 in the case of *Canterbury v. Spence*. The *Canterbury* court specifically rejected both the professional standard and the subjective patient-based standard and instead declared that “the test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked.” The court created an objective patient-based standard by focusing on the “reasonable person” as opposed to the individual patient. The court defined a risk as material “when a reasonable person, in what the physician knows or should know to be the patient's position, would be likely to attach significance to the risk or cluster of risks in deciding whether or not to forego the proposed therapy.” After the *Canterbury* decision, courts

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37 464 F.2d 772 (D.C. Cir. 1972). The case involved the post-surgical paralysis of a young man whose surgeon downplayed the seriousness of the proposed back surgery by responding to the patient’s mother’s question regarding surgical risks that they were “not anymore than any other operation.” *Id.* at 777.

38 *Id.*

39 *Id.*

40 *Id.*
throughout the country articulated a similar disclosure standard.\textsuperscript{41}

Thus, by the early 1970s, the doctrine of informed consent put the patient very much in control of his medical destiny in that the physician was required to not only appropriately inform the patient of the available options but also to obtain the patient’s consent before proceeding with any medical intervention. However, for informed consent to truly empower the patient, the patient had to have the correlative right to refuse unwanted medical therapy; informed consent had to be balanced by informed refusal, otherwise the entire process would be a sham.\textsuperscript{42} If a patient could not refuse an unwanted intervention and the physician could force the intervention upon the patient, what was the point of the process of informed consent? Informed refusal raises no issues if, when presented with a choice between various options, the patient chooses option A instead of option B. But what if the patient refuses potentially life-sustaining therapy and the withholding or withdrawing of that therapy would likely result in the patient’s

\textsuperscript{41} See Beauchamp and Childress, supra note ____, at 88.

\textsuperscript{42} See David B. Waisel and Robert D. Truog, Informed Consent, \textit{87 Anesthesiology} 968 (1997) (noting that “the concept of informed consent must accept the possibility of informed refusal”).
death? Did informed refusal include decisions that could hasten the death of the patient?

The first major case that raised issues of the right to refuse unwanted life-sustaining medical therapy was that of Karen Ann Quinlan.\textsuperscript{43} In Quinlan, the New Jersey Superior Court found that a competent patient had a privacy interest in refusing unwanted medical therapies.\textsuperscript{44} The court further extended patient autonomy by allowing surrogate decision-makers to exercise this right on behalf of incompetent patients and allowed Ms. Quinlan’s father to authorize the removal of her ventilator.\textsuperscript{45}

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\textsuperscript{43} Matter of Quinlan, 355 A.2d 647, 654 (N.J. 1976). Ms. Quinlan was a young woman who lapsed into a persistent vegetative state after sustaining a respiratory arrest, likely secondary to a combination of alcohol and drugs. \textit{Id.} Her father sought to have her ventilator removed. \textit{Id.}

\textsuperscript{44} \textit{Id.} at 663-4.

\textsuperscript{45} \textit{Id.} at 671. However, Ms. Quinlan did not die when the ventilator was removed. She was kept alive, by artificial hydration and nutrition, in a nursing home for an additional nine years until her death from pneumonia in 1985. Robert D. McFadden, Karen Ann Quinlan, 31, Dies; Focus of ’76 Right to Die Case, NEW YORK TIMES, June 12, 1985.
After the Quinlan decision, other jurisdictions decided similar cases. All concluded that a competent patient had the right to refuse unwanted medical therapy and that this right trumped the state’s interests in preserving life and protecting the integrity of the medical profession. The jurisdictions were divided on which evidentiary standards to use for patients who lacked decision making-capacity. Some jurisdictions required the surrogate to make decisions based on “clear and convincing” evidence of the patient’s prior wishes, when competent, and

46 See e.g., Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977) (holding that the right of privacy and the right of informed consent permitted the withholding of chemotherapy from a profoundly retarded man with leukemia); In re Conroy, 486 A.2d 1209 (N.J. 1985) (recognizing that while a common law right to refuse unwanted therapy existed, clear and convincing evidence was necessary for a surrogate decision-maker to authorize withholding or withdrawing of therapy for an incompetent patient); Conservatorship of Drabick, 200 Cal. App. 3d 185 (Cal.App.6.Dist. 1988) (acknowledging the “legal fiction” that a person’s right to choose survives incompetence and noting that society is best served by allowing surrogate decision makers to choose based on the patient’s interests).
others allowed the surrogate to act in the patient’s “best interests” if the patient’s wishes were unknown or unclear.47 Moreover, state legislatures across the country developed advance directives and living wills in response to the common theme of nearly all of these cases that the dying patient had not made clear his or her wishes regarding life-sustaining therapy.48 The idea behind the advance directive or living will is that a person can state his or her preference to withhold or withdraw life-sustaining therapy in the event of a terminal or irreversible condition in advance. Additionally, such instructions would be binding on the health care team and the surrogate decision makers.49

47 See Cantor, supra note 1 at 190-1.
49 See James A. Tulsky, Advance Care Planning, in ETHICS IN PRIMARY CARE (Jeremy Sugarman ed., McGraw-Hill, 2000)(providing an excellent review of advance directives and advanced planning). However, some authors argue that living wills and advance directives have failed to provide the benefits that justified their development. See Angela Fagerlin and Carl E. Schneider, Enough: The Failure of the Living Will, 34 HASTINGS CENT. REP. 30 (2004) (concluding that “a crescendoing empirical literature and
Several questions were left unsettled after Quinlan and its progeny. One question was what constituted life-sustaining therapies and did the concept included artificial hydration and nutrition. A second question was could states impose a clear and convincing evidence standard on surrogate decision-making regarding life-sustaining therapies. The Supreme Court answered both of these questions in the affirmative in the 1990 case of Cruzan v. Director.\textsuperscript{50} In Cruzan, the Court assumed that a competent person has a “liberty interest” under the Due Process

persistent clinical disappointments reveal that the rewards of the campaign to promote living wills do not justify its costs. Nor can any degree of tinkering ever make the living will an effective instrument of social policy”).

\textsuperscript{50} Cruzan v. Director, 497 U.S. 261, 266 (1990). Ms. Cruzan was rendered incompetent as a result of a severe motor vehicle accident that left her in a persistent vegetative state. \textit{Id.} She was kept alive by artificial hydration and nutrition. \textit{Id.} Her parents sought withdrawal of the artificial hydration and nutrition when it became clear that she had virtually no chance of recovering conscious functioning. \textit{Id.} at 267. The Missouri Supreme Court held that there was no clear and convincing evidence of Ms. Cruzan’s wishes and thus her parents lacked authority. \textit{Id.} at 268.
Clause in refusing unwanted medical treatment, including artificial hydration and nutrition, while holding that the Missouri could impose a clear and convincing evidence burden for surrogate decision-makers when the patient was incompetent.\textsuperscript{51}

In the aftermath of the \textit{Cruzan} decision, the legal mechanisms for patients or their surrogates to refuse unwanted medical treatments were firmly established and rarely required judicial review. Patient autonomy grounded the right of competent patients to refuse unwanted medical therapies, including life-sustaining therapies, either through advance directives or by directly refusing such therapies. When the patient lacked capacity to make a decision, the appropriate surrogate decision-maker was empowered to make the decision based either on the patient’s wishes, if known, in a process

known as substituted judgment, or based on the patient’s best interests.\textsuperscript{52}

In a span of under 15 years, the courts created a legal framework to handle the issue of physician-driven overtreatment that recognized the right of an autonomous patient to refuse unwanted medical interventions, even if such a refusal would hasten the death of the patient.\textsuperscript{53} However, all of these cases were based on a fact pattern which always included a health care team recommending continued treatment while the patient’s family or surrogate decision-makers wanted the treatment withdrawn. The guidance of Quinlan and Cruzan could not directly apply to demands for overtreatment from the other end of the spectrum, namely the reverse fact pattern where the health care team

\textsuperscript{52} The exact standards vary from jurisdiction to jurisdiction. In Texas, for example, the surrogate is required to make decisions based on “knowledge of what the patient would desire, if known.” See Tex. Health & Safety Code Ann. § 166.039(c) (2003).

\textsuperscript{53} This Article does not argue that decisions such as Quinlan and Cruzan created a medical utopia where patient wishes were always followed. However, the Article does argue that the decisions created the framework and mechanisms to allow patients, or their surrogates, to refuse unwanted medical treatments over the objections of their healthcare professionals.
recommended discontinuation of life-sustaining treatments while the families or surrogates demanded continuation of the treatments.

III. Patient Driven Overtreatment and Medical Futility

There are two ends of the spectrum regarding the problem of medical overtreatment. As noted above, patient autonomy grounded the right of the patient to refuse unwanted physician-driven overtreatment.54 However, in the late 1980s, clinicians and ethicists began dealing with problem cases on the other end of the spectrum, that of patient or surrogate-driven overtreatment.55 The concept of medical futility emerged as a response to the perceived problem of patient-driven overtreatment. Typical cases involved dying patients or patients in a persistent vegetative state whose surrogate decision-makers demanded continuation of life-sustaining therapies that the health care team believed were no longer beneficial or appropriate for the patient.56 The basic argument was that physicians and other health care professionals had no duty to

54 See supra section II.
56 See Schneiderman, supra note____; see also Halevy and Brody, supra note ______.
provide medical interventions that were futile or that provided no benefit. General agreement exists that if the desired intervention were truly futile, there would be no duty on the part of the health care team to provide the intervention. An accepted definition is important to translate the concept into operational policies which could deal with the problem of patient-driven overtreatment. However, the issues were how to define what was futile and who would define it.

Initial attempts at defining futility focused on substantive definitions. A widely cited definition proposed defining a therapy as medically futile either quantitatively as the intervention had a less than one percent chance of success or qualitatively as permanent unconsciousness or permanent dependence on ICU care. Organizations representing various factions in medicine and many individual scholars offered definitions of futility.

57 For example, if a patient requested a heart transplant for a hangnail, few people, if any, would argue that a physician had an obligation to provide the demanded therapy.

58 See Schneiderman, supra note

59 See Ethics Committee, American College of Physicians Ethics Manual, 117 ANNALS INTERNAL MED. 947 (1992) (providing an example of physiologic futility when allowing that “[i]t is appropriate for
However, critics argued that there were significant flaws with all of the proposed substantive definitions. A major criticism was that the concept of futility was too value laden physicians to write a do-not-resuscitate (DNR) order when resuscitation would not restore circulation and breathing—for example, in progressive multisystem organ failure”; see also The Hastings Center, Guidelines on the Termination of Life-Sustaining Treatment in the Care of the Dying, 19 (Indiana University Press 1987) (noting that “[i]f a treatment is clearly futile in the sense that it will not achieve its physiologic objective and so offers no physiologic benefit to the patient, there is no obligation to provide the treatment”); see also American Thoracic Society, Withholding and Withdrawing Life-Sustaining Therapy, 144 Am. Review Respiratory Diseases 726 (1991) (claiming that “[a] life sustaining intervention is futile if reasoning and experience indicate that the intervention would be highly unlikely to result in meaningful survival for that patient…Survival in a state of permanent unconsciousness…may generally be considered as having no value for such a patient”; see also Society of Critical Care Medicine, Task Force on Ethics, Consensus Report on the Ethics of Foregoing Life-Sustaining Treatments in the Critically Ill, 18 Critical Care Med. 1435 (1990).
to allow for a workable definition.\textsuperscript{60} Even those in favor of the concept of futility argued that none of the proposed substantive definitions could be developed into workable operational policies.\textsuperscript{61} Based on the confusing and conflicting proposed definitions of futility, the Council of Ethical and Judicial Affairs, the subgroup within the American Medical Association which develops ethics policies for the organization, concluded

\textsuperscript{60} See \textit{e.g.}, Robert D. Truog, Alan S. Brett, & Joel Frader, \textit{The Problem with Futility}, 326 \textit{New Eng. J. Med.} 1560 (1992).

\textsuperscript{61} See Baruch A. Brody and Amir Halevy, \textit{Is Futility a Futile Concept?}, 20 \textit{J. Med. & Philosophy} 123 (1995) (arguing that there were four general types of substantive definitions of futility proposed by various groups and that none of the four types satisfied criteria for translating the definitions into operational policies); Baruch A. Brody and Amir Halevy, \textit{The Role of Futility in Health Care Reform}, in \textit{Health Care Crisis? A Search for Answers} (Robert I Misbin, et.al. ed., University Publishing Group 1995) (developing further the argument against substantive definitions of futility and introducing the concept of a procedural based definition).
in 1994 that futility “cannot be meaningfully defined.”62 But the group, recognizing the importance of creating a mechanism to address the problem of patient-driven overtreatment, noted that “denial of treatment [demanded by patients or surrogates] should be justified by openly stated ethical principles and acceptable standards of care.”63

A different approach to medical futility was proposed by a consortium of hospitals in Houston, Texas.64 The group acknowledged that futility could not be substantively defined. However, the group instead proposed a multi-step procedural


63 Id.

64 See Amir Halevy and Baruch A. Brody, supra note 11 at 573 (detailing a nine-step policy that created an institutional review process for the “Determination of Medically Inappropriate Interventions,” which “balances patient autonomy with professional and institutional integrity”). The Houston guidelines intentionally did not use the term “futility” because of the pejorative connotations that the term had attained in the medical ethics literature and instead focused on “medically inappropriate” therapies. Id.
policy that was “based on open and fair processes involving patients, physicians and institutions,” which would analyze each case individually.65 The group likened this approach to the prior judicial approach regarding pornography, noting that “we conclude[d] that we need to treat futility as the courts have treated pornography, acknowledging that while it cannot be defined, we certainly know it when we see it.”66 Several months after the publication of the Houston policy, the Council and Ethical and Judicial Affairs of the American Medical Association shifted its policy on futility. It noted that “the difficulties of defining futility are balanced with the need to have an operational understanding of it.”67 Additionally they

65 Id.

66 Id; see also Jacobellis v. State of Ohio, 378 U.S. 184, 197 (1964) (J. Stewart concurring) (“I shall not today attempt further to define the kinds of material I understand to be embraced within that shorthand description; and perhaps I could never succeed in intelligibly doing so. But I know it when I see it. . .”); see also Paul Gewirtz, On 'I Know it When I See It', 105 YALE L.J. 1023 (1996)(defending the approach in value-laden and context dependent situations).

67 Council on Ethical and Judicial Affairs, Medical Futility in End-of-Life Care, CEJA Report 2-I-96 available at
decided that futility needed to be defined “on a case-by-case basis, taking full account of the context and individuals involved.” 68 After summarizing the literature and the arguments in favor of such an approach, they concluded that “health care institutions, whether large or small, adopt a policy on medical futility” and that “policies on medical futility should follow a due process approach.” 69

Parallel to the scholarly debate regarding medical futility were several court cases that pointed out the difficulties in determining who had ultimate authority regarding futile or inappropriate therapies. The first widely cited case was that

http://www.ama-assn.org/ama1/pub/upload/mm/369/ceja_2i96.pdf;
see also Council on Ethical and Judicial Affairs, American Medical Association, Medical Futility in End-of-Life Care: Report of the Council on Ethical and Judicial Affairs, 281 J. AM. MED. ASS’N 937 (updating the original report and emphasizing that the “fair process approach also provides a system for addressing the ethical dilemmas regarding end-of-life care without need for recourse to the court system”).

68 Id.

69 Id. The recommended policy in the Council’s report was very similar to the policy outlined in the Houston guidelines. See Id.
of Helga Wanglie.\textsuperscript{70} In a case described as “the opposite of Cruzan,” Hennepin County Medical Center sought to obtain judicial approval to remove the ventilator from an 87 year old woman in a persistent vegetative state.\textsuperscript{71} Ms. Wanglie’s medical odyssey began with a broken hip after she tripped over a rug in December 1989.\textsuperscript{72} She suffered several cardiac arrests during her rehabilitation process in the subsequent months and lapsed into a persistent vegetative state in May 2000.\textsuperscript{73} The health care team


\textsuperscript{71} See Lisa Belkin, As Family Protests, Hospital Seeks and End to Woman’s Life Support, New York Times, Jan. 10, 1991 at A1 (citing Arthur Caplan, director of the Center for Biomedical Ethics at the University of Minnesota).


\textsuperscript{73} Id. A persistent vegetative state is “a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain-stem autonomic functions.” The Multi-Society Taskforce on PVS, Medical Aspects of the
caring for Ms. Wanglie believed that continued aggressive support, including the ventilator, was medically inappropriate and attempted to obtain the family’s consent to withdraw treatment.\textsuperscript{74} The family refused, citing their religious view regarding life-sustaining therapies and Ms. Wanglie’s prior wishes.\textsuperscript{75} The hospital petitioned the court to remove Mr. Wanglie as her guardian and substitute an alternative guardian who would agree to remove the life-sustaining therapy.\textsuperscript{76} The probate court judge disagreed and refused to remove Mr. Wanglie as his wife’s conservator noting that “[h]e is in the best position to...

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\textsuperscript{74} See Belkin, supra note____ (citing Dr. Michael Belzer, medical director of the Hennepin County Medical Center, who noted that “[w]e don’t feel that physicians are obliged to provide inappropriate medical treatment that is not in the patient’s medical interest . . . this hospital has the technology to keep 50 Helga Wangelies alive for an indefinite period of time. That would be the easy thing to do. The harder thing is to say just because we can do it, do we have to do it?”)

\textsuperscript{75} Id.

\textsuperscript{76} See Capron, supra note____.
investigate and act upon Helga Wanglie’s conscientious, religious and moral beliefs.”

Ms. Wanglie died three days after the ruling. Thus, in the first widely publicized case involving patient-driven overtreatment, a court refused to create a mechanism to allow the health care team to stop what they considered futile or medically inappropriate treatment.

The second prominent case was that of Baby K. Baby K was born in 1992 in a Virginia hospital and was diagnosed in utero with anencephaly. The standard of care for such infants is

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77 Associated Press, Judge Rejects Request by Doctors to Remove a Patient’s Respirator, NEW YORK TIMES, July 2, 1991 at A 12.
78 See Capron, supra note ____.
79 In the matter of Baby K, 16 F.3d 590 (4th Cir. 1994).
80 Id. at 592. Anencephalic infants are born without a cerebral cortex. They have a brain stem which allows for vegetative functions but such an infant would be permanently unconscious. Moreover, the prognosis for such infants is so dire that the American Medical Association once proposed, and later withdrew because of heavy criticism, that such infants be considered as organ donors for infants in need of solid organ transplants. See American Medical Association Council on Ethical and Judicial Affairs, The Use of Anencephalic Neonates as Organ Donors, 273 J. AM. MED. ASS’N 1614 (1995); see also Charles W. Plows,
supportive care and comfort measures only and the hospital recommended that the infant not be placed on a ventilator. However, Baby K’s mother insisted that the infant be provided with ventilator support whenever the infant developed difficulty breathing on her own. After multiple months shuttling between a nursing home and the hospital’s intensive care unit, the hospital sought a declaratory judgment that they were not obligated to provide respiratory support or other aggressive treatment. In addition to amicus briefs filed in support of the hospital by the American Academy of Pediatrics and the Society of Critical Care Medicine, Baby K’s guardian ad litem and her father joined in the hospital’s request. The district court denied the motion, holding that under the “Emergency Medical Treatment and Active Labor Act (EMTALA), the Rehabilitation Act of 1973, and the Americans with Disabilities Act, the Hospital is legally obligated to provide ventilator

Reconsideration ofAMA Opinion on Anencephalic Neonates as Organ Donors, 275 J. AM. MED. ASS’N 443 (1996)(withdrawing the opinion that anencephalic infants could be used for organ donations).

81 In the Matter of Baby K, 16 F.3d at 592-3.
82 Id. at 593.
83 Id.
84 Id.
treatment to Baby K.” 85 The Fourth Circuit upheld the decision in a two-to-one decision on the basis of EMTALA. 86 However, two years later, the Fourth Circuit severely limited the holding in Baby K by noting that “[t]he case [Baby K] did not present the issue of the temporal duration of that obligation [to provide

85 Matter of Baby K, 832 F.Supp. 1022, 1031 (E.D.Va. 1993). The court also considered constitutional issues, the Child Abuse Amendments of 1984, and the Virginia Medical Malpractice Act but did not base the ruling on these issues. Id.

86 Baby K, 16 F.3d 590, 598 (noting that “[i]t is beyond the limits of our judicial function to address the moral or ethical propriety of providing emergency stabilizing medical treatment to anencephalic infants . . . EMTALA does not carve out an exception for anencephalic infants . . . [and] because EMTALA does not provide for such an exception, the judgment of the district court is affirmed”). EMTALA is the federal law that seeks to prevent the problem of patient “dumping” for financial reasons. For a more detailed review of EMTALA, see Tiana M. Lee, An EMTALA Primer: The Impact of Changes in the Emergency Medicine Landscape on EMTALA Enforcement and Compliance, 13 ANNALS HEALTH L. 145 (2004).
life-sustaining treatment], and certainly did not hold that it was of indefinite duration.” 87

In 1995 the first futility case to go to a jury trial resulted in the hospital prevailing. 88 Ms. Gilgunn was a 71 year old woman in poor health with multiple medical problems who entered Massachusetts General Hospital (MGH) in June 1989 for

87 Bryan v. Rectors and Visitors of the Univ. of Va., 95 F.3d 349, 352 (4th Cir. 1996)(holding that the University of Virginia Hospital’s decision to unilaterally enter a do-not-resuscitate order, over the objections of the patient’s family, which resulted in her death, did not violate EMTALA).

surgery to repair a hip fracture. Prior to surgery, she developed uncontrollable seizures, which resulted in irreversible brain damage that left her comatose. Her daughter, acting as the surrogate decision-maker with the approval of Ms. Gilgunn’s spouse and other children, told the physicians that her mother would have wanted everything done for her. Her doctor turned to the MGH version of an ethics committee, the Optimum Care Committee, for authorization to enter a do-not-resuscitate order into Ms. Gilgunn’s chart. The committee granted permission and the no-not-resuscitate order entered into the chart over the daughter’s objection on August 7, 1989; Ms. Gilgunn died on August 10, 1989. Ms. Gilgunn’s family filed suit. The hospital’s rationale for the unilateral order, as identified by defense expert witness John Paris, an ethicist at Boston College and a Jesuit priest, was that the hospital did not have to abide by the surrogate’s wishes because Ms. Gilgunn

89 See Gina Kolata, Withholding Care From Patients: Boston Case Asks, Who Decides?, NEW YORK TIMES, April 3, 1995 at 1; see also Paris, supra note .

90 Id.

91 Id.

92 Id.
was so ill that resuscitation would have been futile.\textsuperscript{93} The jury took two hours to find for the hospital and the involved doctors.\textsuperscript{94}

Thus, in the three major cases which litigated the question of who had decision making authority in medical futility cases, the courts split with two decisions siding with the family as surrogate decision-makers and one siding with the health care team. Without clear legal guidance, efforts to develop the futility concept shifted to the legislative arena.

IV. Texas Advance Directives Act

Texas became the first state to pass legislation which created a specific process-based futility mechanism when it passed the Advance Directives Act in 1999.\textsuperscript{95} However, the history

\textsuperscript{93} Id. Additionally, Paris noted that “[w]e now have the idea that not only does patients rights mean that I can turn down any treatment but we have the idea that patients and their surrogates can demand treatment and physicians are obligated to provide it. This is madness. This isn’t what medicine is about.” See Kolata, supra n.____.

\textsuperscript{94} See Gina Kolata, Court Ruling Limits Rights of Patients, NEW YORK TIMES, April 22, 1995 at 6.

\textsuperscript{95} TEX. HEALTH & SAFETY CODE ANN. §166.046 (2003). The process is referred to as the “futility” process throughout this Article
of the legislation is rather circuitous. In 1997, Senator Moncrief introduced into the Texas Legislature Senate Bill 441, which “would have amended and consolidated laws regarding advance directives issued by terminally ill patients or their families to withhold or withdraw life-sustaining procedures.”

Additionally, the bill provided that “physicians and health care facilities would have been shielded from civil liability for following advance directives when done ‘in good faith’ rather than ‘unless negligent.’” However, the Texas Right to Life organization, which was already incensed by the Houston futility consortium rallied against the legislation. Opponents of the

since that is how it is commonly referred to in the scholarly literature and in the press. However, the relevant section of the statute does not use the term “futility” and instead refers to “medically inappropriate” treatments. Id.

96 House Research Organization, Texas House of Representatives, Vetoes of Legislation-The 75th Legislature, No.75-16, at 31.

97 Id.

98 See Burke J. Balch, Houston Hospitals Propose Involuntary Euthanasia, NAT’L RIGHT TO LIFE NEWS, Nov. 14, 1996, at 20 (quoting National Right to Life Executive Director David O’Steen stating that “[e]very American, not just those in the Houston area, has reason to fear for the lives of family members unless prompt
bill cited the Houston futility policy “as an example of how doctors and hospitals support procedures to ‘force death on patients against their will and the will of their families.’”\(^{99}\)

The Right to Life organization claimed that section 166.046(b) of the bill authorized involuntary euthanasia since it stated that “[a] physician, or health care professional acting under the direction of a physician, is not civilly liable for failing to effectuate a qualified patient’s directive.”\(^{100}\) The action is taken. The Texas Legislature must act quickly to protect patients against the arrogant and discriminatory betrayal of medical ethics and basic human rights involved in giving unelected hospital committees the arbitrary and unbridled power to decide who shall live and who shall die”\(^9\).


\(^{100}\) Texas Right To Life Committee, Inc, If Patients Can Choose to Die Shouldn’t They Also be Able to Choose to Live?, press release 1997. Ironically, the applicable version of the advance directive in S.B. 414 only allowed patients to refuse life-sustaining therapy, and thus, the provision that the Right to Life organization believed would have authorized a futility decision actually protected physicians who chose not to
Legislature passed the bill, but it was subsequently vetoed by then Governor George W. Bush who, citing the concerns raised by the Right to Life organization, claimed that the bill “contains several provisions that would permit a physician to deny life-sustaining procedures to a patient who desires them.”\textsuperscript{101} Senator Moncrief believed that the pressure exerted by the Right to Life organization prompted the Governor’s veto.\textsuperscript{102}

\textsuperscript{101} Veto Proclamation by the Governor of the State of Texas, George W. Bush, June 20, 1977.

\textsuperscript{102} See House Research Organization, supra n.\underline{____} (noting Moncrief’s response that “[t]he governor’s vague explanation of his decision suggests that he vetoed this bill not because of what it is, but because of what it is not. The religious zealots on the fringe of the Republican party tried hard to tack their own extremist agenda onto this bill. They wanted to gut existing advance directive procedures; abolish the current collaborative approach between care givers, patients and family members; undermine the professional and ethical judgment of trained physicians and prohibit the involvement of family members in the
After the veto, a multidisciplinary taskforce was appointed by the Governor’s office and by legislative leaders because the parties recognized the need to update the law on advance directives in Texas.\footnote{See Fine, supra n.________}

The taskforce, which included physicians, nurses, attorneys, and hospital representatives, among others, also included representatives of the National Right to Life Committee.\footnote{Id.; see also Rick Casey, Right to Life Backed Law That Irks Wife, HOUSTON CHRON. March 11, 2005, at B1 (reporting that “Burke Balch [director of the National Right to Life’s Powell Center for Medical Ethics] flew in from Washington ’20-25 times’...to negotiate the law and its amendment”).} After a series of negotiations, the taskforce drafted compromise legislation that had the support of end of life event of their loved ones. The Governor was obviously swayed by this extremist element.”). See also Robert L. Fine, The Texas Advance Directives Act of 1999: Politics and Reality, 13 H.E.C. FORUM 59, 63 (2001)(noting that “this veto was clearly issued under the influence of the National Right to Life Committee” which was “particularly disturbed by the...Houston hospital consortium guidelines.” Fine also notes that 1997 revisions “did not even deal [with futility]”). Id. at 63.
all parties including the National Right to Life Committee.\textsuperscript{105} The legislation became the Texas Advance Directives Act of 1999, which passed the Texas legislature and was signed by then Governor George W. Bush.\textsuperscript{106} The Act accomplished much of the Legislature’s original goals of consolidating the three prior Texas advance directive mechanisms, the Directive to Physicians, the Durable Power of Attorney for Healthcare, and the Outpatient Do Not Resuscitate policy into one statute.\textsuperscript{107}

The final version of the Advance Directives Act of 1999 also included section 166.046 subtitled “Procedure if not effectuating a directive or treatment decision.”\textsuperscript{108} This section creates an “extrajudicial due process mechanism relying on

\textsuperscript{105} See Casey, supra note ___; see also Elizabeth Heitman and Virginia Gremillion, \textit{Ethics Committees Under Texas Law: Effects of the Texas Advance Directives Act}, 13 H.E.C. FORUM 82 (2001) (noting that “[i]ronically ... the new law ultimately gives institutions, physicians, and ethics committees far greater discretion over the discontinuation of end-of-life treatment than even the most ardent proponent of hospital futility policies could have envisioned”).

\textsuperscript{106} TEX. HEALTH & SAFETY CODE ANN. §§ 166.001-305 (2003).

\textsuperscript{107} See Heitman and Gremillion, supra note ____

\textsuperscript{108} TEX. HEALTH & SAFETY CODE ANN. § 166.046 (2003).
community standards . . . to resolve disputes about futile treatment at the institutional level rather than the courts."\textsuperscript{109} The section outlines steps that an institution has to follow if the attending physician wishes to not provide life-sustaining, against the wishes and demands of the patient, or the patient’s surrogate decision-maker.\textsuperscript{110} The first step is referral of the case to an “ethics or medical committee.”\textsuperscript{111} The patient or surrogate decision-maker must be given “a written description of the ethics or medical committee review process and any other

\textsuperscript{109} Fine, \textit{supra n.____} at 67.

\textsuperscript{110} \textsc{Tex. Health \\& Safety Code Ann.} § 166.046 (2003).

\textsuperscript{111} \textsc{Tex. Health \\& Safety Code Ann.} § 166.046(a) (2003). The ambiguity of this requirement has raised issues by scholars who note that both the original Houston policy (\textit{supra note ___}) and the policy recommended by the American Medical Association (\textit{supra note ___}) had more detailed requirements for the committee. Heitman and Gremillion note that “[t]he open-ended definition of the review committee is a serious concern.” See Heitman and Gremillion, \textit{supra note ___} at 95. See also David M. Zientek, \textit{The Texas Advance Directives Act of 1999: An Exercise in Futility?}, 17 \textsc{H.E.C. Forum} 245,253 (2005) (detailing concerns regarding the “failure of the new Texas statute to provide any guidance about the composition of the ethical or medical committee”).
policies and procedures related to this section adopted by the health care facility."\textsuperscript{112} The patient or surrogate must be informed at least forty-eight hours prior to the meeting of the committee.\textsuperscript{113} The patient, or the surrogate decision-maker, must also be given a copy of the registry of providers maintained by the Texas Health Care Information Council as well as a copy of the standard “Statement Explaining Patient’s Right to Transfer” found in section 166.052.\textsuperscript{114} The patient or surrogate is “entitled to attend the meeting; and receive a written explanation of the decision reached during the review


\textsuperscript{113} \textit{Id.}

\textsuperscript{114} \textit{Tex. Health & Safety Code Ann.} § 166.046(b)(2)-(3) (2003). An amendment in 2003 added a provision that the Texas Health Care Information Council create and maintain an internet based registry “listing the identity of and contact information for health care providers and referral groups, situated inside and outside this state, that have voluntarily notified the council they may consider accepting or may assist in locating a provider willing to accept transfer of a patient . . .” \textit{See Tex. Health & Safety Code Ann.} § 166.053 (2003).
process." If the committee affirms that the requested treatment is “medically inappropriate”, then the hospital’s “personnel shall assist the physician in arranging the patient’s transfer to: (1) another physician; (2) an alternative care setting within that facility; or (3) another facility.” If, ten days after the written notification of the committee’s decision, transfer has not been accomplished, the hospital may unilaterally withdraw the medically inappropriate treatment.

Finally, the legislation makes provisions for the “appropriate district or county court,” at the request of either the patient or the patient’s surrogate, to extend the ten day waiting period, but “only if the court finds, by a preponderance of the evidence, that there is a reasonable expectation that a physician or health care facility that will honor the patient’s directive will be found if the time extension is granted.”

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117 Tex. Health & Safety Code Ann. § 166.046(e) (2003) (noting that “the physician and the health care facility are not obligated to provide life-sustaining treatment after the 10th day”).

Thus, Texas became the first state to have a statute create an extra-judicial procedural mechanism to resolve cases where the health care team was opposed to providing life-sustaining therapies that they believed to be medically inappropriate.\(^\text{119}\)

In spite of its ground-breaking position nationally and the attention that the Act received in the medical and ethics literature, the Act’s futility mechanism received relatively scant attention and functioned as designed for several years.\(^\text{120}\)

\(^{119}\) Prior state-level legislation was much more general. For example, Virginia amended the Health Care Decisions Act in 1992 by adding that “nothing in this article shall be construed to require a physician to prescribe or render medical treatment to a patient that the physician determines to be medically or ethically inappropriate. See Keith Shiner, Medical Futility: A Futile Concept?, 53 WASH. & LEE L. REV. 803, 810 (1996) (citing VA. CODE ANN. § 54.1-2990).

\(^{120}\) Personal communication with Virginia Gremillion, Memorial-Hermann Hospital Ethics Committee, regarding data she collected regarding the use of the §166.046 futility mechanism. See also Robert L. Fine and Thomas W. Mayo, Resolution of Futility by Due Process: Early Experiences with the Texas Advance Directives Act, 138 ANNALS INTERNAL MED. 743 (2003) (chronicling the experiences of the Baylor University Medical Center in Dallas with the
However, the futility mechanism of the Act was recently thrust into public attention by the confluence of two well publicized cases in the Houston area with the national fixation over the case of Terri Schiavo.\footnote{Dina Cappiello and Todd Ackerman, \textit{Schiavo case differs from 2 situations in Houston / Texas statute wouldn't apply to a dispute such as the one in Florida}, \textit{Houston Chron.} March 21, 2003, at A4 (explaining that the difference between the Schiavo case in Florida and the Sun Hudson and Spiro Nikolouzos cases in Texas). For information regarding the Schiavo case, see C. Christopher Hook and Paul S. Mueller, \textit{The Terri Schiavo Saga: The Making of a Tragedy and Lessons Learned}, 80 Mayo Clinic Proceedings 1449 (2005) (detailing the medical, ethical, and legal history of the complex case of Terri Schiavo. Ms. Schiavo, a woman in a persistent vegetative state, was the subject of a prolonged legal between her husband and her parents regarding withdrawing of artificial hydration and nutrition).} These two cases have resulted in significant media attention in Texas and nationally and were even the subject of questions raised to spokesperson of futility process created by the Act); see also Heitman and Gremillion, supra note\_121
President George W. Bush during a press briefing on Air Force One.\textsuperscript{122}

The first case was that of Sun Hudson. Sun Hudson was born in September 2004 at St. Luke’s Episcopal Hospital in Houston, Texas and was immediately transferred to the neonatal intensive care unit at Texas Children’s Hospital, where he was diagnosed with thanatophoric dwarfism, a rare and universally fatal form of neonatal dwarfism.\textsuperscript{123} Sun’s physicians explained to Sun’s

\textsuperscript{122} Press Gaggle by Scott McClellan Aboard Air Force One, March 21, 2005, available at: 
\url{http://www.whitehouse.gov/news/releases/2005/03/20050321-2.html} 
(defending the President’s actions as Governor of Texas regarding the Advance Directives Act and claiming that:

“[t]he legislation that he signed into law actually provided new protections for patients. He had previously vetoed legislation in 1997, when he was Governor, which essentially would have sanctioned current law in Texas that allowed hospitals to stop providing life-sustaining treatment -- because under Texas law, prior to the passage of the ’99 legislation that he signed, there were no protections. And so this legislation was supported by many; it enjoyed strong bipartisan support; concerned citizens, various groups came together to support this legislation and put in place new protections for patients”).

\textsuperscript{123} See Lance Lightfoot, \textit{Incompetent Decisionmakers and Withdrawal of Life-Sustaining Treatment: A Case Study}, 33 J.L. Med. \& Ethics 851 (2005) (providing a detailed account of the entire Sun Hudson case from the perspective of the General
mother --- the appropriate surrogate decision-maker under Texas law --- that his condition was incompatible with life and that they recommended that all life-sustaining treatment be withdrawn.\textsuperscript{124} Ms. Hudson insisted on continued treatment, expressing her belief that her son would live.\textsuperscript{125} When numerous attempts to negotiate a resolution with Ms. Hudson failed, the case was referred to the hospital’s Biomedical Ethics Committee for review as required by section 166.046 of the Texas Advance Directives Act.\textsuperscript{126} After reviewing the case, the committee affirmed the physicians’ position that the continuation of life-sustaining treatment was medically inappropriate.\textsuperscript{127} Because of

\begin{thebibliography}{10}
\bibitem{124} Id.
\bibitem{125} Id.
\bibitem{126} Id.
\bibitem{127} Id.
\end{thebibliography}
concerns that Ms. Hudson possibly lacked decision-making capacity, Texas Children’s Hospital assisted Ms. Hudson in retaining an attorney. Suit was filed against Texas Children's Hospital in November 2004 seeking injunctive relief and monetary damages. The judge issued a temporary injunction that ended up lasting five months. The injunction required Texas Children's Hospital to continue to provide Sun with life-sustaining treatment. During this time period, forty hospitals

128 Id. Ms. Hudson had a psychiatric history and named her son Sun because she believed that she had been impregnated by the sun. Id. This action was not required by the Advance Directives Act. See TEX. HEALTH & SAFETY CODE ANN. § 166.046 (2003).

129 See Lightfoot, supra note___, fn. 23 (identifying the case as “Wanda Hudson, as the Mother of Sun v. Texas Children's Hospital, 2004-66483 (333rd Judicial District, Harris County, Texas, filed November 23, 2004). For jurisdictional reasons, Ms. Hudson's attorney subsequently moved to dismiss the case in the state district court and re-filed it in the Harris County, Texas, probate court. See Wanda Hudson, as the Mother of Sun v. Texas Children's Hospital, No. 352,526 (Probate Ct. No. Four, Harris County, Texas, filed Dec. 29, 2004”).

130 Id.

131 Id.
across the country refused to accept Sun in transfer. On February 16, 2005, Judge William McCullough ruled that Texas Children's Hospital could discontinue the life-sustaining therapy. The case was appealed to the Texas court of appeals, which sent it back to the probate court to resolve a procedural question. The procedural issue was resolved and on March 14, 2005, McCullough made “the landmark decision” to allow Texas Children’s Hospital to proceed with the withdrawal of life-sustaining therapy as provided by section 166.046 of the Advance Directives Act. Texas Children's Hospital withdrew life-sustaining treatment the next day, and Sun Hudson died in his mother's arms.

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133 See Leigh Hopper and Todd Ackerman, “Inside of Me, My Son is Still Alive”- Baby Dies After Hospital Removes Breathing Tube-Case is the First in Which a Judge Allowed a Hospital to Discontinue Care, HOUSTON CHRON., March 16, 2005 at A1.


135 See Hopper and Ackerman, supra note ___

136 Id.
The second case was that of Spiro Nikolouzos.\textsuperscript{137} Spiro Nikolouzos was a retired engineer who had suffered brain damage in a motor vehicle accident more than a decade ago.\textsuperscript{138} He had been in a persistent vegetative state since a 2001 bleeding episode related to a shunt in his brain.\textsuperscript{139} He had been cared for by his wife at home until February 2005, when he was brought to St. Luke’s Episcopal Hospital in Houston, Texas, after he apparently experienced bleeding around his tube feeding site. Mr. Nikolouzos’ condition deteriorated further in the hospital and his physicians recommended withdrawal of all life-sustaining treatment.\textsuperscript{140} His wife refused, and the hospital invoked the futility policy under section 166.046. The hospital ethics committee affirmed that continued life-sustaining treatment


\textsuperscript{138} See Todd Ackerman, \textit{Transfer Resolves Life-Support fight-San Antonio Facility takes in Local Man, Ending Dispute Between Family, St. Luke’s, Houston Chron.,} March 21, 2005 at A1 (citing Dr. David Pate, Chief Medical Officer at St. Luke’s Episcopal Hospital regarding a chronology of events regarding Nikolouzos).

\textsuperscript{139} \textit{Id.}

\textsuperscript{140} See Cappiello and Ackerman, \textit{supra} note____ (citing Dr. Pate as describing Nikolouzos “on a scale of 1 to 10-10 being worst case vegetative state—Nikolouzos is a 10”).
would be medically inappropriate. Mrs. Nikolouzos filed suit, seeking several temporary restraining orders and an extension of the ten-day waiting period; all of her motions were denied because the judge did not believe that the evidence reflected “a reasonable expectation that a doctor or another health care facility would honor Mr. or Mrs. Nikolouzos’ directive.” The family appealed, and the appellate court dismissed the appeal for want of jurisdiction. In a concurring opinion, Judge Fowler sought to assure the family that even if the court had jurisdiction, they would not have prevailed on the merits of the case. Prior to removal of the life-sustaining therapy, a nursing home in San Antonio, Texas, which had rejected his transfer nine days prior, agreed to accept him in transfer.

141 Jerry D. Bullard, Texas Court of Appeals Update-Substantive, The Appellate Advocate, Summer 2005 at 72.

142 Nikolouzos, 162 S.W.3d at 680.

143 Id. at 682. Additionally, Judge Fowler raised questions about the statute, noting that “the statute is replete with procedural problems that threaten to sabotage a family’s attempt to obtain additional time under §166.046 to locate alternative care for its loved ones.” Id. at 683.

144 See Ackerman, supra note__.
The owner cited “a right to life philosophy.” Mr. Nikolouzos died two months later.

These two cases have focused attention on the futility mechanism in the Texas Advance Directives Act. As noted above, they have received national media attention and were the subject of many internet bloggers. There have been calls to reform the law from some quarters and to repeal it from others. The Texas Legislature held a hearing on August 9, 2006

145 See Todd Ackerman, Burial Set for Man at Center of Debate Over Life Support—His Widow Says She Plans to Fight Law that Allows Hospital to Decide to End Patient Care, HOUSTON CHRON., June 3, 2005, at B9.

146 Id.

147 Two other cases, those of Andrea Clark and Kalilah Roberson-Reese, have also received media attention, with members of both families testifying at the legislative hearing. See Todd Ackerman, Families Urge Change to State Futile-Care Law, HOUSTON CHRON., August 10, 2006, at B1.

148 See Terry M. Neal, Political Expediency Abounds in the Schiavo Case, WASH. POST, March 23, 2005 (noting that the Sun Hudson case “generated the most buzz among bloggers this week”).

149 See Ackerman, supra note____
which drew approximately 150 people, most of whom were there at
the invitation or urging of Texas Right to Life and the Texas
chapter of Not Dead Yet, a disability rights organization. Additionally, the futility mechanism became an issue in the
recent Texas gubernatorial election with all of the major
candidates calling for it’s change in the next legislative
session. It is very likely that the Texas Advance Directives

150 Id. The disability rights movement has been concerned about
the potential abuse of policies to withdraw life-sustaining
treatments from persons with disabilities. James L. Werth, Jr.,
Concerns about Decisions Related to Withholding/Withdrawing
Life-Sustaining Treatment and Futility for Persons with
Additionally, the Health Law and Policy Institute at the
University of Houston Law Center also contributed a position
paper outlining possible procedural reforms for the Act. Ronald
L. Scott, Texas Legislature Should Address Procedural
Inadequacies in Advance Directives Act, September 2006 at
kolouzos%201.pdf.

151 See Ackerman, supra note___ (“Discontent with the law has
already infiltrated the gubernatorial race. Comptroller Carole
Keeton Strayhorn and independent candidate Kinky Friedman say

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Act Coalition, the formal title of the taskforce that created the compromise Act in 1999, will recommend “some sort of consensus reform.”

V. Professional Integrity as a Counterbalance to Patient Autonomy

Lost in the haggling and arguments over the futility mechanism is the discussion of the fundamental question raised by the entire debate. More important than whether a patient is given three days or ten days or fourteen days for transfer is the underlying philosophical basis for the determination of medical inappropriateness. The fundamental question is what

the favor the law’s abolition, and Democratic nominee Chris Bell says he favors reform. Gov. Rick Perry favors the legislative review to determine whether the law has flaws”).

152 Id.; see also Testimony of Greg D. Hooser to the House Committee on Public Health regarding Interim Charge #4, August 9, 2006 (providing, as chairman of the coalition, information regarding the history of the development of the Texas Advance Directives Act and also proposed changes).

153 The waiting period between the determination by the “ethics or medical committee” that the requested life-sustaining intervention is medically inappropriate and the time that the health care institution is no longer obligated to provide the
to do when an end-of-life conflict, where the patient or surrogate decision-maker requests medical treatment that the healthcare team believes to be medically inappropriate or futile, cannot be resolved through negotiation and communication. Should the patient’s or the family’s wishes always trump the professional standards of the physicians, or should the professional standards of the medical profession occasionally trump the demands of the patient or family? This Article argues that professional standards and professional integrity must, with appropriate procedural safeguards, trump the medically inappropriate demands of a patient or family.

It is well established, both legally and ethically, that a competent patient has the right to refuse unwanted medical interventions, and in appropriate circumstances, a surrogate decision-maker can authorize withdrawal of life-sustaining treatment for a patient without capacity. The legal right is grounded in a liberty interest under the due process clause. In the ethics literature, the right to refuse unwanted interventions is grounded in the principle of patient autonomy.

See Fine, supra note____; see also Hooser, supra note____.

154 See Section II, supra.
But a liberty interest in refusing treatment and an autonomy-based interest in refusing treatment does not necessarily bestow a corresponding right to receive whatever treatment is demanded.155 A right to refuse is considered a negative right; a right to receive whatever is demanded is a positive right.156 Negative legal rights are accorded significantly more protection in the United States.157 The courts have held that a patient has a liberty interest in refusing unwanted medical interventions,

155 Harris v. McRae, 448 U.S. 297, 318 (1980) (holding in an abortion case that while a liberty interest protected by the due process clause prohibits unwarranted interference in an individual’s freedom of choice by the government, “it does not confer an entitlement to such funds necessary to realize all of the advantages of that freedom”).

156 See Frances M. Kamm, Harming, Not Aiding, and Positive Rights, 15 PHILOSOPHY & PUBLIC AFFAIRS 3, 16 (1986).

157 See David P. Currie, Positive and Negative Constitutional Rights, 53 U. CHI. L. REV. 864 (citing Judge Posner in Jackson v. City of Joliet, 715 F.2d 1200 (7th Cir.) that the Constitution “is a charter of negative rather than positive liberties...The men who wrote the Bill of Rights were not concerned that the Government might do to little for the people but that it might do too much to them”).
but the courts have also held there is “no general right, based upon either the Constitution or federal statutes” to health care services.\textsuperscript{158}

But arguing that negative rights are more protected than positive rights and that patient autonomy is not inviolate does not provide a justifiable basis for a futility mechanism. Rather, it is essential to ground a futility mechanism on a societally approved and defensible ethical basis to counter critics of futility policies who argue that allowing the health care profession the right to refuse to provide medically inappropriate treatment would be indefensible because of imposed values.\textsuperscript{159} The integrity of the medical profession provides such a grounding.\textsuperscript{160}

\textsuperscript{158} See Cruzan, 497 U.S. 261 at 279; see also Wideman v. Shallowford Cmty. Hosp., 826 F.2d 1030, 1032-3 (11th Cir. 1987). Philosophers also argue that individuals have strong negative rights but weak or non-existent positive rights. See Kamm, supra note\textsuperscript{____} at 16 (citing Robert Nozick, Anarchy, State, and Utopia (Basic Books 1974).

\textsuperscript{159} See Halevy and Brody, supra note\textsuperscript{____}

The importance of protecting the integrity of the medical profession is not a new concept in American jurisprudence nor in medical ethics. In the early cases that established a right to refuse unwanted medical interventions, the courts identified the “integrity of the medical profession” as one of the state interests that had to be considered in balance with the patient’s desire to refuse treatment.\(^{161}\) The U.S. Supreme Court that “[t]he patient’s autonomy is limited when it becomes a demand for treatment the physician honestly believes is not medically indicated, is injurious to the patient, or is morally repugnant”). See also Judith F. Daar, A Clash at the Bedside: Patient Autonomy v. A Physician’s Professional Conscience, 44 Hastings L.J. 1241, 1289 (1993)(arguing that “[i]f patient autonomy is to have meaning, recognition must also be given to a physician’s moral autonomy . . . when patients clash with their physicians over treatment choices, the principle of autonomy does not automatically require that the physician be forced to comply”).

\(^{161}\) See Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 425 (Mass. 1977)(surveying prior decisions involving the question of the right of an individual to refuse medical treatment and concluding that “maintaining the ethical integrity of the medical profession” is a state
has reaffirmed the importance of the state interest in maintaining the integrity of the medical profession in an assisted suicide case. The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research affirmed the importance of professional integrity when noting that “health care professionals or institutions may decline to provide a particular option because that choice would violate their conscience or professional judgment, though in doing so they may not abandon the patient.”

The point is not that professional integrity automatically trumps patient autonomy, but that both values must be respected interest). For a more complete discussion of the analysis of the integrity of the medical profession, see Brian C. Kalt, Death, Ethics, and the State, 23 HARV. J. L. & PUB. POL’Y 487(2000).

Washington v. Glucksberg, 521 U.S. 702, 731 (1997) (stating that “[t]he State also has an interest in protecting the integrity and ethics of the medical profession”).

President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life Sustaining Treatment: Ethical, Medical and Treatment Decisions, (1983) at 3.
and that both values counterbalance each other. Both values must be weighed in making these difficult end-of-life decisions. In the case of a patient refusing unwanted life-sustaining medical treatment, patient autonomy controls because of the negative right of the patient to be left alone. In the case of the patient demanding life-sustaining medical treatment that the health care team believes to be medically inappropriate, professional integrity should prevent physicians and other health care professionals from being forced to provide treatments that violate the integrity of the medical profession.

This argument also underscores the problem with focusing on the length of time to allow for transfer. The integrity of the medical profession does not vary from hospital A to hospital

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164 The concept of professional integrity must be distinguished from individual integrity based on personal conscience and values. The former constitutes the accepted practice of the profession and it is grounded in the tenets of the profession. The latter is based on the values and morals of an individual physician or health care professional and is often invoked in so-called "conscience clause" provisions. See generally Martha S. Swartz, "Conscience Clause" or "Unconscionable Clauses": Personal Beliefs versus Professional Responsibilities, 6 Yale J. Health Pol’y L. & Ethics 269 (2006).
B. If an appropriate review mechanism has affirmed that continued provision of the disputed treatment would violate the integrity of the medical profession, the willingness of a single health care professional to provide the treatment does not make it medically appropriate. And as noted above, the morals and values of a single health care provider, while important for the individual, does not constitute the standards of the profession.\textsuperscript{165}

The above is not meant to argue that the current version of the Texas futility mechanism is perfect. Rather, the law should be reformed to strengthen its overarching goal of creating an extra-judicial mechanism to resolve conflicts regarding the appropriateness of medical treatment. This mechanism should properly protect the interests of all of the involved parties, namely the patient and his or her family and the health care professionals and health care institutions involved in the care of the patient.\textsuperscript{166}

\textsuperscript{165} See Halevy and McGuire, supra note 3, at 42.

\textsuperscript{166} Detailed recommendations for reform are beyond the scope of this Article. However, recommendations regarding strengthening the composition and expertise of the “medical or ethics committee” and incorporating a higher level of required review of the relevant scientific literature have been made elsewhere.
VI. Conclusion

Dealing with death and dying is always difficult and emotionally draining for loved ones and caregivers, even in the best of circumstances. Cases involving conflicts between the health care team and the patient or the patient's surrogate decision-maker, are not the best of circumstances. In those rare situations where there is disagreement about providing or withdrawing life-sustaining treatment, the challenges are even greater.167 Negotiation, compromise, and improved communications can work out most such cases.168 However, not all cases can be resolved, which is why the American Medical Association

See Heitman and Gremillion, supra note____. Similar recommendations have been made by others. See Zientek, supra note____.

167 See Hooser, supra note____ (reporting on data from nine Texas hospitals that the futility mechanism, section 166.046, had been invoked only fifty-seven times out of approximately 36,000 deaths in a five-year period and had only resulted in life-sustaining treatment withdrawn over the objection of the family in only twenty-six cases).

recommended a fair process dispute resolution mechanism and why Texas created the futility mechanism in the Advance Directives Act.\textsuperscript{169}

The principle of patient autonomy has grounded the right of patients to refuse unwanted medical interventions for over a generation. However, patient autonomy can not be unlimited and must be balanced against competing principles. While it grounds the right to refuse, it cannot create an unlimited right to demand.

The integrity of the medical profession is an appropriate counterbalance to patient autonomy and should be the basis for a fair and open deliberative process that can, when necessary, place appropriate limits on the demands of individual patients or families for medical therapies that are medically inappropriate. Critics who argue that any limitation would result in imposing value judgments on patients and families are correct. However, imposing the values of the patient or family on the health care institution and society is as much of a value judgment. No resolution of this complex issue can ever be value free. The key is whether the resolution mechanism is based on defensible values supported by society.

The extra-judicial dispute resolution mechanism found in the Texas Advance Directives Act, should, with minor amendments, serve as a national model that appropriately balances the interests of all involved parties in these difficult cases while still leading to a defensible solution. It would be incredibly ironic if we, as a society that does not consider access to appropriate health care to be a fundamental right and that allows millions of citizens to be uninsured, would consider it a fundamental right of individuals to have access to medically inappropriate treatments.\textsuperscript{170}

\textsuperscript{170} See Wideman v. Shallowford Cmty. Hosp., 826 F.2d 1030, 1032 (11th Cir. 1987) (noting that “we can discern no general right, based upon either the Constitution or federal statutes, to the provision of medical treatment and services…”); see also Judith Graham, Insurers Offer Plan to Cover Uninsured, CHI. TRIBUNE, November 14, 2006 (citing a figure of 45 million uninsured individuals in the United States).