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Communicating Past The Conflict: Solving The Medical Futility Controversy With Process-based Approaches

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COMMUNICATING PAST THE CONFLICT: SOLVING THE MEDICAL FUTILITY CONTROVERSY WITH PROCESS-BASED APPROACHES¹

*Bryan Rowland**

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¹ For sake of brevity, “medical futility” will be referred to as “futility.”

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INTRODUCTION

Mr. J is a 75-year-old male who, because of a previous leg amputation and the need for chronic dialysis, lived with and was cared for by his two sons.... He suffers from complications of diabetes and is admitted to the hospital for amputation of his other leg.

Approximately five days post-amputation [of his second leg], Mr. J suffered a respiratory arrest, was resuscitated and transferred to the ICU. This began Mr. J's five month odyssey of multiple transfers into and out of all three adult ICUs as a result of multiple resuscitations. Because the sons refused to accept anything less than a miraculous healing for their father, they adamantly refused to agree to DNR [Do Not Resuscitate] status. On one occasion they demanded that the resuscitation be continued, resulting in a 55 minute resuscitative effort. They viewed each successful resuscitation as "minor miracles" that would result in a final "major miracle" (Mr. J being able to leave the hospital and give testimony to his cure).

An Ethics Rapid Response consult approximately three months into his hospital stay acknowledged the impossible nature of the dilemma faced and advocated an emphasis on meeting Mr. J's symptom management needs for the duration of his hospital stay.

The chasm between the physicians' perspective of futile care and the sons' perspective of miracles widened and deepened over the five-month period. The physicians struggled with being put in an untenable position of violating the ethical principles of beneficence, non-maleficence, and justice (both personal and distributive) while the sons stood firm on their legal surrogate decision making role, viewing themselves as protecting their father's autonomy by making decisions for him that they believed to be in his best interest.

Mr. J died on the 147th day of his hospital stay, surrounded not by family, but rather by the Code Blue team who attempted one final, but futile, resuscitation effort.²

² Sr. Julie Manternach, Chaplain, A Tale of an End-of-life Journey, Address at the Project of Compassionate Health Care and Responsible Stewardship, Aug. 26, 2005. Patient and family's identification have been changed for confidentiality purposes.

Mr. J is but one example of patients experiencing prolonged pain due to technological advances and raised expectations of patients and their families.³ Many patients experience extended periods of suffering during the dying process due to patient or family members' desires to do everything possible.⁴ Modern medical technology has produced a group of "half-way technologies" that allow physicians to "maintain the physiologic basis of life but not reverse pathologic processes."⁵ Often these treatments prove non-beneficial and even harmful.⁶

Should a physician be allowed to withdraw or withhold continued treatment, even over the objections of a competent patient or their representative? Or should the patient or their representative dictate treatment regardless of their physician's clinical judgment or the cost of the demanded treatment? These are some of the questions the medical community⁷ has been grappling with since the mid 1980s.⁸

These cases differ from the traditional right-to-die cases in which the patient or proxy refuses treatment. In the early right-to-die cases, e.g. Karen Quinlan⁹ and Nancy Cruzan, patients or their families refused

³ See generally Health Council of South Florida, Inc., The Medical Futility Guidelines of South Florida, 4, (2000), available at <http://www.healthcouncil.org/publications/futility.html>.

⁴ See Gay Moldow et al., *Why Address Medical Futility Now?*, MINN. MED., (June 2004), available at <http://www.mmaonline.net/publications/MNMed2004/June/Moldow.html> (last visited Mar. 21, 2006).

⁵ *Id.*

⁶ *Id.*

⁷ "Medical community" refers to the healthcare systems: physicians, other clinicians, ethicists, hospital administrators and attorneys.

⁸ Paul R. Helft et. al, *The Rise and Fall of the Futility Movement*, 343 NEW ENG. J. MED. 293, 293 (2000), available at <http://content.nejm.org/cgi/content/full/343/4/293?maxtoshow=&HITS=20&hits=20&RES>.

⁹ Yet this early right-to-die case began "this nation on a course away from medical paternalism, and toward a future in which the wishes of patients would prevail. Patient autonomy is ... the gold standard for ethical decision-making when recommended care conflicts with a patient's wishes." Jerry Menikoff, *Demanded Medical Care*, 30 ARIZ. ST. L.J. 1091, 1091 (1998).

medical treatment.¹⁰ These right-to-die cases established patients' rights to refuse life-sustaining treatment or demand its withdrawal.¹¹ The concepts of privacy, patient autonomy, and informed consent established that patients (not their physicians) should make treatment decisions.¹² Paradoxically, the battle today between physicians and patients is not likely to regard patients and physicians disagreeing over care that physicians recommend. Rather, the battle consists of patients or their surrogates demanding care that their physicians believe is futile or medically inappropriate.¹³ Has the right to refuse treatment been extended to encompass a positive right to demand medical treatment regardless of cost or physicians' clinical judgment?¹⁴ Does legal precedent establish a patient's right to demand treatment or a physician's right to refuse treatment deemed futile?

This comment will suggest that the solution to the conflict between physicians and patients regarding futile care is a process-based approach to deciding end-of-life decisions.¹⁵ Part I of this comment will

¹⁰ See generally *In re Quinlan*, 355 A.2d 647 (N.J. 1976); *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990).

¹¹ Keith Shiner, Note, *Medical Futility: A Futile Concept?*, 53 WASH. & LEE L. REV. 803, 805 (1996). *Quinlan* and *Cruzan* are often cited as the beginning of patient/surrogate rights to demand the withdrawal or withholding of life-sustaining treatment based on a patient's right to privacy. Philip G. Peters, *When Physicians Balk at Futile Care: Implications of the Disability Rights Laws*, 91 NW. U. L. REV. 798, 798 (1997).

¹² See Shirley E. Sanematsu, *Taking a Broader View of Treatment Disputes beyond Managed Care: Are Recent legislative efforts the cure?*, 48 UCLA L. REV. 1245, 1254-55 (2001); Matthew S. Ferguson, *Ethical Postures of Futility and California's Uniform Health Care Decisions Act*, 75 S. CAL. L. REV. 1217, 1217 (2002).

¹³ Menikoff, *supra* note 9, at 1091.

¹⁴ In healthcare decisions, a "positive" right is the right to be free to make any healthcare decisions one desires. ALAN MEISEL & KATHY L. CERMNARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISION MAKING*, § 13.06 (3d ed. Supp. 2004).

¹⁵ "The emphasis of the [due process] approach ... is on fair process between parties rather than on ... definition ... of the parties. Professional standards ... patient rights, intent standards, and family or community involvement usually should be accommodated in the process of deliberation." AMA Council on

begin with a review of the various attempts at defining futility, including identifying what is not futility. It will reveal the futility of the search for an absolute definition of medical futility "since it is inherently a value-laden determination."¹⁶

Part II will review the evolution of addressing futile care in the United States (alternatively "U.S.") and Great Britain (alternatively "U.K."). This section will focus on the major cases that have provided patients and their families the legal right to die¹⁷ and the progression of patients and their families moving away from the "paternalistic" physician¹⁸ towards demanding treatment that physicians and facilities have deemed futile in the U.S..¹⁹ Further analysis of federal and state statutory laws will be reviewed to determine the current legal status of futility as a positive or negative right in the U.S..

Contrasted with the status of futility in the U.S. will be the review of futility in the U.K. that "mere life for its own sake is not worth spending money on if there is an opportunity cost for those resources that could otherwise be spent providing definite benefits and high probability."²⁰ The British National Health System has court-appointed authority to ration care based on "clinical guidelines that blend efficacy of outcomes, quality of life judgments, and economics."²¹ This comment will also review British Case Law, which has established no duty to

Ethical and Judicial Affairs, *Medical Futility in End-of-Life Care*, 281 JAMA 937, 942 (1999) available at <http://www.icampus.ucl.ac.be/medoc/jama.htm>.

¹⁶ *Id.* at 941.

¹⁷ *In re Quinlan*, 355 A.2d 647 (N.J. 1976); *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990).

¹⁸ Anne Federwisch, *Medical futility: Who has the power to decide?*, Nurseweek, July 2, 1998, <http://www.nurseweek.com/features/98-7/limits.html> (last visited Mar. 21, 2006).

¹⁹ See e.g., *In Re: The Conservatorship of Helga M. Wanglie*, 7 ISSUES L. & MED. 369 (1991-92). (include a parenthetical)

²⁰ Howard Brody & Raanan Gillon, *Futile Care Treatment: Perspectives from the United States and United Kingdom*, 75 U. DET. MERCY L. REV. 529, 540 (1998).

²¹ *Id.* at 543; Wesley J. Smith, *The English Patient*, The Weekly Standard, May 30, 2005, available at http://www.weeklystandard.com/Utilities/printer_preview.asp?idArticle=5645&R=C6DB31.

continue life-prolonging treatment even if the patient may desire it.²² Further attention will be paid to the recent saga of Leslie Burke²³ in the U.K. and his suit against the General Medical Council (GMC) regarding his contention that the withholding of artificial nutrition against his desires would be a violation of his human rights under the European Convention of Human Rights (ECHR).²⁴

Part III of this comment will conclude with the argument for establishing process-based approaches to address medical futility as an established communication standard from which physicians and patients or families may successfully address futility. Process-based approaches in the U.S. will be identified and the “legality” of the process-based approach will be explored. Finally, the evolution of the Texas Advanced Directive statute, the only codified process-based approach to futility in the U.S., will be discussed and its ramification on patients in Texas will be reviewed.²⁵

I. DEFINING FUTILITY

“I shall not today attempt further to define the kinds of material I understand to be embraced.... [b]ut I know it when I see it....”²⁶ These words illustrate the Supreme Court’s frustration in its fifty-year struggle at describing obscenity.²⁷ This reaction to an attempt at defining “obscene” is similar to the confusion and controversy surrounding attempts to define “medical futility.”²⁸

²² *In re J*, [1992] 3 W.L.R. 507 (Fam), [1993] Fam. 15 (Eng.).

²³ Leslie Burke, an English citizen, suffers from a degenerative brain condition and was fearful that artificial nutrition might be withheld from him.

²⁴ The UK enacted the European Convention on Human Rights Act of 1998 on Oct. 2, 2000.

²⁵ See TEX. HEALTH & SAFETY CODE ANN. § 166.046 (Vernon 2003).

²⁶ *Jacobellis v. Ohio*, 378 U.S. 184, 197 (1964). Famous quote from Justice Potter exemplifies the struggle the Supreme Court has had in their attempts at defining what speech qualifies as “obscene.”

²⁷ *Id.*

²⁸ Anne Federwisch, *Medical Futility. Who has the Power to Decide?*, Nurse Week, July 2, 1998, <http://www.nurseweek.com/features/98-7/limits.html>.

“Numerous definitions of futility have been proposed, but none have been universally accepted.”²⁹ Some definitions of futility appear under inclusive, others over inclusive, while others appear both under inclusive and over inclusive.³⁰ The American Medical Association’s (AMA) Council on Ethical and Judicial Affairs has stated, “[F]utility ... cannot be meaningfully defined.”³¹ The issue with developing a “standard” clinical definition of futility is that it contains value judgments about the characteristics of a particular patient’s life.³² Consequently, what one physician might consider futile may not be considered futile by the patient or her family or even other physicians.³³

A. *Why Define Futility?*

There are several reasons for clearly defining what futility means and determining how to manage medical care in those situations. First, one should query at what point care or intervention is futile in light of the existence of “half-way technologies” permitting physicians to maintain certain biological systems even when cognitive human life is not evident.³⁴ Second, modern day medicine related to life-sustaining interventions is expensive.³⁵ Even though physicians are instructed to do everything within their power to benefit their patients, the AMA’s

²⁹ AscensionHealth.org, Health Care Ethics: Futility, <http://www.ascensionhealth.org/ethics/public/issues/futility.asp> (last visited Mar. 25, 2006).

³⁰ Mark Strasser, *The Futility of Futility?: On Life, Death, and Reasoned Public Policy*, 57 MD. L. REV. 505, 514 (1998).

³¹ AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS: CURRENT OPINIONS WITH ANNOTATIONS E-2.035 (2004), available at <http://www.ama-assn.org/ama/pub/category/8389.html>.

³² Lanie Olmstead, Medical Futility, <http://www.wramc.amedd.army.mil/departments/Judge/futility.htm> (last visited Mar. 25, 2006).

³³ *Id.*

³⁴ Moldow et al., *supra* note 4.

³⁵ See Gilmer et al., *The Costs of Nonbeneficial Treatment in the Intensive Care Setting*, HEALTH AFF., July–Aug. 2005, at 962 (stating that in the United States, services provided in the ICU accounts for 20 percent of inpatient costs, currently 0.9 percent of the annual gross domestic product).

Council on Ethical and Judicial Affairs Code of Medical Ethics do allow physicians to review ethically appropriate criteria related to cost when determining treatment for their patients.³⁶

Third, dilemmas relating to futility have resulted in high-profile court cases, such as those of *Gilgunn*, *Burke*, *Baby K*, and *Wangile*.³⁷ Patients and health care systems would benefit if the medical community could resolve futility issues outside the arena of the courtroom. Finally, medical-decision authority has moved away from the more paternalistic model of physicians determining the course of treatment, with little or no input from the patient and their family, towards the patient and family having more decision-making power.³⁸ A clear definition of futility would be helpful to patients and their family when asserting their authority in the face of a physician's refusal to provide care.

B. What Futility is Not

Perhaps one can better understand the concept of "futility" by examining how futility is *not* defined. Futility does not refer to patients or treatments in a general sense. Futility applies to the treatment being performed or considered on an individual patient at a particular point in

³⁶ AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS, *supra* note 30, at E-2.03, available at http://www.ama-assn.org/apps/pf_new/pf_online?f_n=resultLink&doc=policyfiles/HnE/E-2.03.HTM&s_t=allocation+of+limited+medical+resources&catg=AMA/HnE&catg=AMA/BnGnC&catg=AMA/DIR&&nth=1&&st_p=0&nth=1&.

³⁷ *In re Baby "K,"* 823 F. Supp. 1022 (E.D. Va. 1993), *aff'd* 16 F.3d 590 (4th Cir. 1994);

Robert J. Dzielak, *Physicians Lose the Tug of War to Pull the Plug: The Debate About Continued Futile Medical Care*, 28 J. MARSHALL L. REV. 733, 748 (1995); *Patient Loses Right-to-Food Case*, BBC News, July 28, 2005, <http://newsvote.bbc.co.uk/mpapps/pagetools/print/news.bbc.co.uk/2/hi/health/4721061.stm> (last visited Mar. 25, 2006); Sisters of Charity of Leavenworth Health System, *Catherine Gilgunn*, http://www.sclhsc.org/about/mission_vision/ethical_issues/catherine_gilgunn.htm (last visited Mar. 25, 2006).

³⁸ Dzielak, *supra* note 37, at 733.

time.³⁹ The treatment being performed or considered can only be considered futile if it does not or will not achieve medicine's goals of benefiting that particular patient.⁴⁰

Futility is not rationing health care.⁴¹ Futility involves decisions regarding the benefit of medical treatment to the patient, while rationing⁴² explores cost consideration and the availability of particular resources in relation to the proposed treatment.⁴³ Rationing is therefore a derivation of Distributive Justice.⁴⁴ As the patient's advocate, a physician should provide care regardless of cost.⁴⁵ If the intervention is deemed

³⁹ LAWRENCE J. SCHNEIDERMAN & NANCY S. JECKER, *WRONG MEDICINE: DOCTORS, PATIENTS, AND FUTILE TREATMENT* 8 (1995) [hereinafter *WRONG MEDICINE*].

⁴⁰ *Id.*

⁴¹ *See id.* at 79.

⁴² An example of medical rationing reasoning:

[Dr. Vincent] finally blurted out. "Look, the guy is already in his 80s. I just don't think it's right to be spending tens or what could be even hundreds of thousands of dollars on him when the best we can do is give him maybe a year or two more of poor quality of life, if that much. Meanwhile look at all the other people – kids, particularly – who have their whole life ahead of them – they're the one we should be giving this treatment to." The other doctors chimed in their agreement

Id. at 66.

⁴³ Shiner, *supra* note 11, at 826.

⁴⁴ "Principles of distributive justice are normative principles designed to allocate goods in limited supply relative to demand" Plato.stanford.edu, *Distributive Justice*, at <http://plato.stanford.edu/entries/justice-distributive/> (last visited Mar. 25, 2006).

⁴⁵ "A physician has a duty to do all that he or she can for the benefit of the individual patient. ... Physicians have a responsibility to participate and to contribute their professional expertise in order to safeguard the interests of patients in decisions made at the societal level regarding the allocation or rationing of health resources." AMERICAN MEDICAL ASSOCIATION, *CODE OF MEDICAL ETHICS*, *supra* note 30, at E-2.03, available at http://www.ama-assn.org/apps/pf_new/pf_online?f_n=resultLink&doc=policyfiles/HnE/E-

futile, however, the physician or facility is not ethically bound to continue treatment no matter the cost (even if the resource is cheap and abundant).⁴⁶

Palliative care should not be considered futile;⁴⁷ in fact, futility disputes could actually be considered the antithesis of palliative care.⁴⁸ In futile care, physicians are giving treatment that may only result in pain and other symptoms without any hope of significant benefit.⁴⁹ Conversely, "palliative care improves the quality of a patient's life, even if the intervention may not prolong the length of survival."⁵⁰

C. Attempts at Defining Futility

To address futility appropriately, the medical community must reach a consensus about a definition or seek some other process from which to address the problem.⁵¹ Several attempts at defining futility warrant mention.

2.03.HTM&s_t=allocation+of+limited+medical+resources&catg=AMA/HnE&catg=AMA/BnGnC&catg=AMA/DIR&&nth=1&&st_p=0&nth=1&.

⁴⁶ "Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients." *Id.* at E-2.035, available at http://www.ama-assn.org/apps/pf_new/pf_online?f_n=resultLink&doc=policyfiles/HnE/E-2.035.HTM&s_t=allocation+of+limited+medical+resources&catg=AMA/HnE&catg=AMA/BnGnC&catg=AMA/DIR&&nth=1&&st_p=0&nth=2&.

⁴⁷ *Id.*

⁴⁸ Joseph J. Fins, *Principles in Palliative Care: An Overview*, RESPIRATORY CARE J. (2000), at <http://www.rcjournal.com/contents/11.00/11.00.1320.asp> (last visited Mar. 25, 2006).

⁴⁹ *Id.*

⁵⁰ Olmstead, *supra* note 32.

⁵¹ ERICH H. LOEWY & ROBERTA S LOEWY, TEXTBOOK OF HEALTHCARE ETHICS 297 (2d ed. 2004).

1. Physiological Futility⁵²

Physiological futility can be described as treatment that will not achieve its physiological goal and therefore will afford no physiological benefit to the patient.⁵³ An example of physiological futility would be a physician prescribing an antibiotic to treat a viral infection. Since antibiotics combat bacteria they would be ineffective in treating viral infections.⁵⁴

Although physiological futility may be the easiest definition of futility to analyze in practice, an approach that only accounts for psychological futility has several problems.⁵⁵ First, such a definition could easily prohibit physicians from properly determining a treatment's futility, because the treatment would maintain a biological function of the body even though the patient may be persistently unconscious or terminally ill.⁵⁶ Furthermore, the value of an intervention cannot be judged by physiological outcome alone. Physiological outcomes often vary, and physicians are often unable to determine when an intervention may be of little or no physiological benefit.⁵⁷ Case law, however, does support the position that when a patient receives no physiological benefit from a treatment, a physician has no legal obligation to provide or continue that course of treatment regardless of patient authorization.⁵⁸

⁵² Physiological is a "characteristic of or appropriate to an organism's healthy or normal functioning" MERRIAM-WEBSTER'S COLLEGIATE DICTIONARY 888 (9th ed. 1991), available at <http://www.m-w.com/dictionary/physiological>.

⁵³ The Medical Futility Guidelines of South Florida, *supra* note 3, at 6.

⁵⁴ Eric M. Levine, *A New Predicament for Physicians: The Concept of Medical Futility, the Physician's Obligation to Render Inappropriate Treatment, and the Interplay of the Medical Standard of Care*, 9 J.L. & HEALTH 69, 74 (1994-1995).

⁵⁵ Menikoff, *supra* note 9, at 1095.

⁵⁶ The Medical Futility Guidelines of South Florida, *supra* note 3, at 6.

⁵⁷ See Ralph Cohen-Almagor, *Language and Reality at the End of Life*, 28 J.L. MED. & ETHICS 267, 270-71 (2000).

⁵⁸ MEISEL, *supra* note 14, at 13-15.

2. Qualitative Futility

Some commentators deem qualitative futility as the most controversial.⁵⁹ Schneiderman and Jecker define the qualitative feature of medical futility as: “[i]f a patient lacks the capacity to appreciate the benefit of a treatment, or if the treatment fails to release a patient from total dependence on intensive medical care.”⁶⁰ In other words, is the patient’s quality of life so diminished (e.g. permanent unconsciousness) that it could be considered futile to continue the patient’s life?⁶¹ Determining the quality of a patient’s life in relation to a given treatment therefore becomes a value judgment, one that physicians are ill qualified to determine alone.⁶²

The qualitative view of futility directly clashes with the notion of patient autonomy.⁶³ Courts have moved away from the paternalistic physicians’ model (under which the physicians could determine the benefits of a treatment for a given patient) towards the principle of patient autonomy.⁶⁴ “Now they [doctors] can sustain life beyond our wildest former expectations, but once patients realize the hollowness of such mechanical life, those patients who want to die [or in the opposite case, the proxy who wants everything possible done] sue their doctors.”⁶⁵

3. Quantitative Futility

Shiner characterizes quantitative futility as a “a treatment [that] has proved ineffective in the last one hundred cases,”⁶⁶ that is, the probability of a given treatment’s success drops so low, that one could

⁵⁹ Menikoff, *supra* note 9, at 1096.

⁶⁰ WRONG MEDICINE, *supra* note 39, at 17.

⁶¹ By this definition, continued medical treatment (e.g. respirator or feeding tube) in a persistently unconscious person would be considered futile since it simply maintains the patient’s chronic vegetative state.

⁶² Menikoff, *supra* note 9, at 1097.

⁶³ Shiner, *supra* note 11, at 830.

⁶⁴ *Id.* at 832.

⁶⁵ Brian C. Kalt, *Death, Ethics, and the State*, 23 HARV. J. L. & PUB. POL’Y 487, 501 (2000).

⁶⁶ Shiner, *supra* note 11, at 828.

consider it futile.⁶⁷ An example of this kind of futility is providing CPR⁶⁸ to an elderly patient with metastatic⁶⁹ cancer.⁷⁰ As more therapeutic options have become available, this struggle with uncertainty can lead to a paralysis of action.⁷¹ If a physician can never be one hundred percent sure that a treatment will fail or succeed, is there not a moral obligation to do anything that might work?⁷² This situation is yet another instance where for individual values will predominate decision making, which again cannot be adequately addressed by physicians alone.

4. Hybrid Quantitative and Qualitative Futility

Scheniderman and Jecker combine the different aspects of quantitative and qualitative into their general definition of futility:

Medical futility means any effort to provide a benefit to a patient that is highly likely to fail and whose rare exceptions cannot be systematically produced. [emphasis in the original]...[T]his definition has a quantitative component (“highly likely to fail”) and a qualitative component (“benefit to the patient”)...[T]he focus of the effort is the patient (derived from the Latin word for ‘to suffer’), not some organ or physiological function or

⁶⁷Menikoff, *supra* note 9, at 1098.

⁶⁸ Contrary to popular belief, “[O]nly about 15% of hospitalized patients in whom resuscitation is attempted will survive to discharge. ... Patients over 70 years of age who have sepsis or metastatic carcinoma, or whose arrest lasts more than 15 minutes are unlikely to survive.” Healthcare Ethics, Cardiopulmonary Resuscitation (2005), <http://www.ascensionhealth.org/ethics/public/issues/cardio.asp> (last visited Mar. 24, 2006).

⁶⁹ Metastatic cancer is cancer that has spread or metastasizes to other areas of the body.

⁷⁰ Olmstead, *supra* note 32.

⁷¹ WRONG MEDICINE, *supra* note 39, at 14.

⁷² *Id.* at 14-15.

body substance...[W]hat is provided is a benefit, not an effect.⁷³

Scheniderman and Jecker stress the provision of “benefit” over “effect,” due to the enormous range of effects that modern medicine can produce on the human body.⁷⁴ Physicians can create or cause multiple effects on even an unconscious patient, yet if these actions have no benefit, the authors argue the treatment is futile.⁷⁵

Although these definitions have been helpful in framing the futility argument, they have been unsuccessful in determining a definitive definition of futility.⁷⁶ Even those who accept the concepts of quantitative and qualitative futility disagree on how to draw the dividing line between futile and non-futile care.⁷⁷

II. FUTILITY IN THE U.S. & U.K.

In the U.K., Charlotte Wyatt was born prematurely requiring ventilation for most of her first three months. She suffers from severe brain, kidney, and lung damage. As a result, Baby Charlotte, as she came to be known, is:

[B]lind, deaf and incapable of voluntary movement or response. It is very highly probable that she will during this winter succumb to a respiratory infection that will prove fatal. That said the unanimous medical evidence also recognizes that in this area there is no such thing as certainty of prognosis or survival.⁷⁸

⁷³ *Id.* at 11-12.

⁷⁴ *Id.* at 12.

⁷⁵ Some examples of these effects include: “adding and subtracting body chemicals, increasing and reducing circulating blood cells, destroying cancer cells, restoring the heartbeat, replacing kidney function, killing bacteria, subduing viruses and fungi....” *Id.*

⁷⁶ Menikoff, *supra* note 9, at 1099.

⁷⁷ *Id.*

⁷⁸ Portsmouth NHS Trust v. Wyatt & Ors, [2004] EWHC (Fam.) 2247 (Eng.).

A British judge held that doctors do not have to attempt resuscitation of Charlotte if she stops breathing.⁷⁹

Now that she has survived past her second birthday, Mr. Justice Hedley has, in turn, discharged his year-old ruling on October 21, 2005 which stated “that doctors would not be acting unlawfully if they decided it was not in the child’s best interests to artificially ventilate her in a life-threatening situation.”⁸⁰ Yet, doctors at St Mary’s Hospital in Portsmouth claim that they still have the final decision in determining the best treatment for Charlotte: “[I]f there is a future disagreement we have a very clear direction from the court ... doctors are not required to ventilate Charlotte when it is not in her best interest to do so.”⁸¹

In the U.S., Baby K was born in an anencephalic state.⁸² She was transferred to a nursing home for ongoing care with an agreement that the hospital would readmit her if she again developed respiratory distress.⁸³ After several re-admissions for respiratory distress requiring ventilator treatment, the hospital sought “declaratory judgment absolving the hospital of liability under the Emergency Medical Treatment and

⁷⁹ *Id.* at 9.

⁸⁰ Timesonline.co.uk, Baby Charlotte wins reprieve on her second birthday, <http://www.timesonline.co.uk/article/0,,2-1836900,00.html> (last visited Mar. 25, 2006).

⁸¹ *Id.*

⁸² Anencephalic state:

Anencephaly is a congenital defect in which the brain stem is present but the cerebral cortex is rudimentary or absent. There is no treatment that will cure, correct, or ameliorate anencephaly. Baby K is permanently unconscious and cannot hear or see. Lacking a cerebral function, Baby K does not feel pain. Baby K has brain stem functions primarily limited to reflexive actions such as feeding reflexes (rooting, sucking, swallowing), respiratory reflexes (breathing, coughing), and reflexive responses to sound or touch. Baby K has a normal heart rate, blood pressure, liver function, digestion, kidney function, and bladder function and has gained weight since her birth. Most anencephalic infants die within days of birth.

In the Matter of Baby K, 832 F. Supp. 1022, 1025 (E.D. Va.) (1993).

⁸³ *Id.*

Active Labor Act (EMTALA)⁸⁴ if the hospital refused to provide ventilator treatment when Baby K next experienced respiratory distress.”⁸⁵

The court ruled that the plain language of EMTALA required that respiratory treatment (life-saving treatment) be given to Baby K.⁸⁶ EMTALA, a U.S. Federal law, requires that life-sustaining treatment be given to any individual who comes to an emergency room requiring emergency treatment.⁸⁷ Some commentators argue that the reasoning of

⁸⁴Emergency Medical Treatment and Active Labor Act (EMTALA) , 42 U.S.C. § 1395dd (2000).

⁸⁵ Strasser, *supra* note 29, at 507.

⁸⁶ *Id.*

⁸⁷ Hospitals with emergency medical departments must provide an appropriate medical screening to determine whether an emergency medical condition exists for any individual who comes to the emergency room seeking treatment. 42 U.S.C. § 1395dd(e)(1) (2000). The statute defines an “emergency medical condition” as including:

[A] medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain) such that the absence of immediate medical attention could reasonably be expected to result in (i) placing the health of the individual ... in serious jeopardy, (ii) serious impairment to bodily functions, or (iii) serious dysfunction of any bodily organ or part.

42 U.S.C. § 1395dd(e)(1)(A)(i)-(iii) (2000);

The Court determined that in the application of EMTALA to Baby K:

[T]he Hospital concedes that when Baby K is presented in respiratory distress a failure to provide ‘immediate medical attention’ would reasonably be expected to cause serious impairment of her bodily functions. *See* 42 U.S.C. § 1395dd(e)(1)(A). Thus, her breathing difficulty qualifies as an emergency medical condition, and the diagnosis of this emergency medical condition triggers the duty of the hospital to provide Baby K with stabilizing treatment ... [s]ince transfer is not an option available... the Hospital must stabilize Baby K’s condition.

Baby K, 832 F.3d at 594.

the court in Baby K regarding EMTALA is “flawed.”⁸⁸ As a result of the decision, Baby K lived until she was two and one-half years old.⁸⁹

These two cases are representative of the futility debates in both the U.S. and U.K.. The British courts usually support rational medical decision-making to withhold or withdraw futile care.⁹⁰ On the other hand, litigated cases in the U.S. usually disallow physicians from withholding or withdrawing life-sustaining medical treatment without the consent of the patient or surrogate.⁹¹

A. The United States

In the U.S., “the withholding and withdrawal of life support is legally justified primarily by the principles of informed consent and informed refusal, both of which have strong support in the common law.”⁹² Patients or their surrogates can either approve the proposed treatment (informed consent) or refuse any and all therapies (informed refusal).⁹³ With this emphasis on patient autonomy has come the evolution of patients demanding not only that care be discontinued, but

⁸⁸ MEISEL, *supra* note 14, at 13-30; Strasser, *supra* note 30, at 508-09.

But the U.S. Court of Appeals did not consider other federal laws (Section 504 of the Rehabilitation Act and Section 302 of the Americans with Disabilities Act) or Virginia state law (Virginia Medical Malpractice Act) as obligating the Hospital to provide care to Baby K, since it determined that EMTALA required the Hospital to render stabilizing treatment. Baby K 832 F.3d at 592.

⁸⁹ Answers.com, The case of Baby K, <http://www.answers.com/topic/baby-k> (last visited Mar. 26, 2006).

⁹⁰ See LE Hagger, *The Human Right Act 1998 and medical treatment: time for re-examination*, 89 ARCHIVES OF DISEASES IN CHILDHOOD 460 (2003) available at <http://adc.bmjournals.com/cgi/content/full/89/5/460#otherarticles> (last visited Mar. 26, 2006).

⁹¹ See, e.g., In the Matter of Baby K, 832 F. Supp. 1022 (E.D. Va.) (1993). See also, 42 U.S.C. § 1395dd; Wanglie, *supra* note 19, at 372 (Hospital denied guardianship); MEISEL, *supra* note 14, at 13-6, 17.

⁹² John M. Luce & Ann Alpers, *Legal Aspects of Withholding and Withdrawing Life Support from Critically Ill Patients in the United States and Providing Palliative Care to Them*, 162 AM. J. RESPIR. CRIT. CARE MED. 2029 (2000).

⁹³ See *id.* at 2029 (stating that physicians are allowed to provide treatment without consent in emergency situations).

also that treatment be provided even when a physician does not recommend it.⁹⁴

Yet, since no definitive definition of futility has been developed, these common law proclamations regarding informed consent and informed denial provide no legal consensus about how futility cases should be addressed in the U.S.⁹⁵ Instead, a variety of conflicting common law and statutory approaches have developed regarding futile care. The only consensus regarding futile care in the U.S. regards physiologic futility.⁹⁶ For example, a physician is under no obligation to continue ventilation of a clinically brain-dead person.⁹⁷

1. The Right to Say No

It has been almost thirty years since the landmark case of Karen Quinlan (*In re Quinlan*) in which the question of withholding or withdrawing life-sustaining treatment from a patient was first determined.⁹⁸ Quinlan was kept alive by a ventilator after she slipped into a persistent vegetative state (PVS).⁹⁹ Her physicians and hospital refused her family's request to terminate ventilator treatment. They

⁹⁴ MEISEL, *supra* note 14 at 13-8 – 9.

⁹⁵ *See id.*

⁹⁶ See discussion on Physiologic Futility *supra* pp. 277-78.

⁹⁷ *See* MEISEL, *supra* note 14, at 13-7.

⁹⁸ *In re Quinlan*, 355 A.2d 647, 662-63 (N.J. 1976).

⁹⁹ PVS was first considered a diagnostic entity in 1972. "Until the 1970's and '80s PVS patients were rarely kept alive for long periods of time." WRONG MEDICINE, *supra* note 38, at 3. More regarding PVS:

Individuals in such a state [Persistent Vegetative State] have lost their thinking abilities and awareness of their surroundings, but retain non-cognitive function and normal sleep patterns. Even though those in a persistent vegetative state lose their higher brain functions, other key functions such as breathing and circulation remain relatively intact. Spontaneous movements may occur, and the eyes may open in response to external stimuli. They may even occasionally grimace, cry, or laugh.

National Institute of Neurological Disorders and Stroke, Coma and Persistent Vegetative State Information Page,
<http://www.ninds.nih.gov/disorders/coma/coma.htm> (last visited Mar. 26, 2006).

recognized that “Karen’s present treatment serves only a maintenance function; ... the respirator cannot cure or improve her condition but at best can only prolong her inevitable slow deterioration and death.”¹⁰⁰

The New Jersey Supreme Court recognized a right of privacy in which the “individual’s right to privacy grows as the degree of bodily invasion increases and the prognosis dims.”¹⁰¹ This right to be left alone is accepted by the U.S. Supreme Court.¹⁰² In allowing Quinlan’s right to privacy, the court recognized a patients’ rights movement giving patients or their guardians the “right to refuse medical treatment, even if that meant death.”¹⁰³ In essence, the family was given the responsibility to do what Karen would have wanted, and if her wishes were not known, they were given the authority to decide as a proxy for her best interest.¹⁰⁴ Karen’s respirator was removed, and she lived unaided in her breathing for another nine years before succumbing to pneumonia.¹⁰⁵

Seven years after the New Jersey Supreme Court decided *Quinlan*, Nancy Cruzan lost control of her car on a road in Missouri and was thrown from her vehicle face down into a water-filled ditch.¹⁰⁶ Paramedics were able to resuscitate Cruzan, but her injuries resulted in a diagnosis of PVS.¹⁰⁷ *Cruzan* would be the first time that the U.S. Supreme Court would address the issue of withholding or withdrawing life-supporting treatment.

After three years of witnessing their daughter’s grotesque physical changes and with a prognosis of PVS until death, Cruzan’s

¹⁰⁰ See discussion of “half-way” technologies *infra* p. 2; Quinlan, *supra*, note 98, at 663.

¹⁰¹ *Id.* at 664.

¹⁰² ARTHUR S. BERGER & JOYCE BERGER, TO DIE OR NOT TO DIE? CROSS-DISCIPLINARY, CULTURAL, AND LEGAL PERSPECTIVES ON THE RIGHT TO CHOOSE DEATH 131 (Praeger Pub.) (1990).

¹⁰³ Robert M. Veatch & Carol M. Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 AM. J.L. & MED. 15 (1992).

¹⁰⁴ *Id.*

¹⁰⁵ Karen Ann Quinlan Hospice, History, at <http://www.karenannquinlanhospice.org/History.htm> (last visited Mar. 26, 2006).

¹⁰⁶ Cruzan, 497 U.S. at 266.

¹⁰⁷ *Id.*

parents had requested that her artificial hydration and nutrition be terminated.¹⁰⁸ The Missouri Supreme court declared that the state had an interest in life that was unqualified; consequently, the court ordered that treatment (artificial nutrition and hydration) must be continued as long as Cruzan was alive.¹⁰⁹ The court stated it would only approve the removal of Cruzan's feeding tube if "clear and convincing" evidence could be established that she would not want to be kept alive in a PVS state.¹¹⁰

The Cruzans appealed their case to the U.S. Supreme Court. But the Court upheld Missouri's evidentiary standard of "clear and convincing" in determining a patient's wishes ruling that due process was not violated by such a standard.¹¹¹ The Court stated "[t]he choice between life and death is a deeply personal decision of obvious and overwhelming finality. We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements."¹¹²

Yet when the case was remanded to the trial level, the trial court accepted testimony from Nancy's friends not presented at any of the early court hearings that she had stated that she would not want to live in a vegetative state. The trial court accepted this additional evidence as "clear and convincing," and the state of Missouri chose not to pursue an appeal.¹¹³ Nancy's medically assisted nutrition and hydration was removed in December of 1990, and she died two weeks later.¹¹⁴ Her family maintained that for them Nancy had died back in 1983, the year of her auto accident.¹¹⁵

Unlike *Quinlan*, the right to refuse life-sustaining treatment in *Cruzan* was firmly grounded by the Fourteenth Amendment's guarantee

¹⁰⁸ See *id.*, at 265.

¹⁰⁹ *Cruzan v. Harmon*, 760 S.W.2d 408, 423-24 (1988).

¹¹⁰ See *WRONG MEDICINE*, *supra* note 38, at 2.

¹¹¹ *Cruzan*, 497 U.S. at 282-83.

¹¹² *Id.* at 281.

¹¹³ *WRONG MEDICINE*, *supra* note 39, at 2.

¹¹⁴ WESLEY J. SMITH, *CULTURE OF DEATH (THE ASSAULT ON MEDICAL ETHICS IN AMERICA)* 68-69 (2000).

¹¹⁵ *WRONG MEDICINE*, *supra* note 39, at 2.

of personal liberty.¹¹⁶ Additionally, “the Supreme Court’s Cruzan ruling significantly extended the Quinlan decision by including artificial nutrition and hydration (tube feedings) as medical care that may be refused or discontinued by the competent patient or surrogate.”¹¹⁷ Thus today, competent patients or their surrogates have a legally protected right to say “no” to any treatment, even life-sustaining treatment.¹¹⁸ *Quinlan* and *Cruzan* established a patient’s right to refuse or demand the withdrawal of life-sustaining treatment. Effectively, this is a “negative” right.¹¹⁹ “This negative right of refusal skewed medical decision-making power in favor of patients.”¹²⁰

The common law doctrine of informed consent provided yet another justification for a patient’s right to refuse life-sustaining treatment.¹²¹ Informed consent means that “prior to agreeing to any

¹¹⁶ Nancy Cruzan has a liberty interest under the Due Process clause of the 14th Amendment. *Cruzan*, 497 U.S. at 278.

¹¹⁷ David B. Waisel & Robert D. Truog, *The End-of-Life Sequence*, 87 J. AM. SOC’Y ANESTHESIOLOGISTS 676 (1997), available at <http://gateway.ovid.com/ovidweb.cgi?T=JS&MODE=ovid&NEWS=n&PAGE=toc&D=ovft&AN=00000542-0000000000-000000>.

¹¹⁸ *Id.*

¹¹⁹ “Negative right” explained:

A negative right embodies the freedom to do what one wants without interference from others. The right to refuse medical treatment is such a right. It is a right to live one’s life without being imposed upon by physicians who, for their own reasons and based on their own values (however benevolent), might wish to compel an individual to receive treatment that [the] individual does not want.

MEISEL, *supra* note 14, at 13-23.

¹²⁰ Dzielak, *supra* note 37, at 747.

¹²¹ *Id.*, “Under common law, a patient normally must consent to medical treatment of any kind. Consent is required to maintain the right of personal inviolability.” *Keiner v. Cmty. Convalescent Ctr.* 549 N.E. 2d 292, 297 (1989). Furthermore, Justice Cardozo viewing this right in the context of medical treatment stated: “Every 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.” *Id.* (quoting *Schloendorff v. Soc’y of New York Hosp.*, 105 N.E. 92, 93 (1914)).

touching of one's body, an individual must be given information about the proposed touching. Judicial decisions [generally hold that] under this doctrine, it is essential for a physician to obtain consent from a patient before starting any procedure or treatment."¹²² Patients are to make the treatment decisions based on the information provided by their physician. The patient has a legally protected right to refuse offered medical treatment under informed consent.¹²³ Therefore, the right-to-die decisions (establishing privacy, liberty, and informed consent for medical treatment) provided patients or their surrogates in the U.S. the right to demand or refuse the withdrawal of life-sustaining treatment.

2. A Right to Demand Treatment

Emboldened with the right to say "no" to medical treatment, patients began to demand that physicians provide medical treatment even if their physician believed the treatment was inappropriate.¹²⁴ Often these demands for continued care come on behalf of the patient by their surrogate.¹²⁵ Although these cases do not directly address the futility issue, they demonstrate the expansion of patients' rights from a negative right to say "no," to a positive right¹²⁶ to demand healthcare (sanctioned by the court), regardless of cost or physicians' recommendations.¹²⁷

¹²² "For a consent to be valid, the physician must give the patient material information about the course of action proposed, the risks of death or harm the procedure may entail, the alternate therapies, and the problems that may arise during the recovery process." BERGER & BERGER, *supra* note 102, at 132.

¹²³ *Id.*

¹²⁴ Dzielak, *supra* note 37, at 744.

¹²⁵ See *In re Wanglie*, *supra*, note 19, at 371. See also *In re Baby K*, 16 F.3d 590 (4th Cir. 1994).

¹²⁶ Meisel on positive and negative rights:

Like a negative right, a positive right envisions that one should be free to do what one wants, but rather than envisioning a freedom *from* - specifically, freedom from interference by others - it envisions a freedom *to* - specifically, freedom to make the most of one's life with the resources that one can legitimately superintend without entrenching on other's freedom to be free from unwanted interference. In the

One of the first cases to address the issue of a “positive” right was Helga Wanglie’s case, in which Wanglie suffered a cardiac arrest that rendered her permanently unconscious.¹²⁸ After several weeks, the physicians treating Wanglie determined that continued respiration was futile and recommended that continued life-sustaining treatment be stopped, but Wanglie’s husband refused to discontinue her care.¹²⁹ Consequently, a lawsuit ensued where Wanglie’s physician attempted to have a conservator appointed to determine the best interest of Wanglie.¹³⁰ Ultimately, the court appointed Mr. Wanglie who, it reported, was in the best position to act on behalf of his wife.¹³¹

The court stated:

No court order to continue or stop any medical treatment for Helga Wanglie has been made or requested at this time. Whether such a request will be made, or such an order is proper, or this Court would make such an order, and whether Oliver Wanglie [Helga’s husband] would execute such an order are speculative matters not now before the Court.¹³²

In this proclamation, the court seems to infer a disregard for physician autonomy, showing recognition that the court’s decision had not directly determined medical treatment for Wanglie, but in sidestepping the clash of values between Wanglie’s physician and family, nonetheless ensured continued care despite medical objection.¹³³

context of medical decision-making, it is the freedom to have whatever medical treatment one might wish.

MEISEL, *supra* note 14, at 13-23.

¹²⁷ *Id.*

¹²⁸ *In re Wanglie*, *supra* note 19, at 374.

¹²⁹ *Id.* at 371.

¹³⁰ *Id.*

¹³¹ *Id.* at 372.

¹³² *Id.* at 377.

¹³³ Judith F. Daar, *Medical Futility and Implications for Physician Autonomy*, 21 AM. J.L. & MED. 221, 224 (1995).

Patients and their families have also invoked federal statutory grounds to demand treatment. The federal statutes invoked as source of a positive right to healthcare include: EMTALA,¹³⁴ § 504 of the Rehabilitation Act of 1973, § 302 of the American with Disabilities Act, and the Child Abuse Amendment of 1984.¹³⁵ Although all these federal statutes can logically be drawn into the debate of patients demanding medical treatment from their physicians, only EMTALA has been successfully invoked to impose a limited duty to continue treatment.¹³⁶

The Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (ADA) prohibit discrimination against the disabled.¹³⁷ Proponents of a positive healthcare right have cited Section 504 of the Rehabilitation Act of 1973 and Section 302 of the Americans with Disabilities Act of 1990 to prohibit attempts at withholding or withdrawing life-sustaining treatment from the handicapped.¹³⁸

Section 504 prohibits discrimination against an "otherwise qualified individual with a disability ... solely by reason of his or her disability ... under any program or activity receiving Federal financial assistance"¹³⁹ (this includes any hospital receiving Medicaid or

¹³⁴ *Supra* note 84.

¹³⁵ Erin A. Nealy, *Medical Decision-Making For Children: A Struggle For Autonomy*, 49 SMU L. REV. 133, 141-52 (1995-1996). *See generally* MEISEL, *supra* note 14, at 13.06[c][1] (covering the several federal statutory 'positive' rights).

¹³⁶ *See* MEISEL, *supra* note 14, at 13-28; *In re Baby "K,"* 16 F.3d 590, 594 (4th Cir. 1994). *See also* Bryan v. Rectors & Visitors of Univ. of Va., 95 F.3d 349 (4th Cir. 1996). Case recognized that EMTALA is an anti-dumping statute, not a federal malpractice statute. EMTALA was created to keep hospitals from turning away patients that needed emergent care. Once that patient is stabilized, the decisions regarding ongoing treatment is up to the discretion of the facility and the treating physicians. Therefore, it was not a violation of EMTALA for a physician to determine that no further life-sustaining treatment should be provided after 12 days of treatment. This decision is consistent with *Baby K*, because the patient in *Baby K* required emergent care for immediate stabilization.

¹³⁷ Nealy, *supra* note 135, at 141-147.

¹³⁸ *Id.* at 146.

¹³⁹ 29 U.S.C. § 794(a) (2000). *See* Nealy, *supra* note 135, at 142-43.

Medicare.)¹⁴⁰ The person must be otherwise qualified to receive the care for there to be discrimination.¹⁴¹ The line of reasoning used to deny claims of discrimination under Section 504 is as follows: “in spite of the birth defect, he or she was ‘otherwise qualified’ to receive the denied medical treatment. Ordinarily, however, if such a person were not so handicapped, he or she would not need the medical treatment and thus would not ‘otherwise qualify’ for the treatment.”¹⁴² A futility decision by a physician would only constitute a violation of Section 504 if the patient was “otherwise” qualified to receive the treatment the physician recommends withholding.¹⁴³ Thus, Section 504 does not mandate a physician having to provide futile care, even if demanded.¹⁴⁴

In contrast, Section 302 of the ADA applies to discrimination at all public accommodations, rather than just Medicaid or Medicare funded facilities.¹⁴⁵ Additionally, Section 302 of the ADA does not refer to a handicapped individual being “otherwise qualified” in regards to the services in question to qualify for discriminatory protection.¹⁴⁶

Section 302 of the ADA states that:

[D]iscrimination includes -- the imposition or application of eligibility criteria that screen out or tend to screen out an individual with a disability or any call of individuals with disabilities [u]nless such criteria can be shown to be necessary for the provision of goods,

¹⁴⁰ MEISEL, *supra* note 14, at 13-31.

¹⁴¹ 29 U.S.C. § 794(a) (2000).

¹⁴² *Johnson v. Thompson*, 971 F.2d 1487, 1493 (10th Cir. 1992), *cert. denied*, 507 U.S. 910 (1993). This decision refers to infants born with birth defects and is in agreement with the “otherwise qualified” reasoning in *United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144, 156 (2d Cir. 1984) “[O]ne would not ordinarily think of a newborn infant suffering from multiple birth defects as being ‘otherwise qualified’ to have corrective surgery performed.” *Id.*

¹⁴³ *See Nealy, supra* note 135, at 144-45.

¹⁴⁴ *Id.*

¹⁴⁵ *See Americans with Disabilities Act of 1990*, 42 U.S.C. § 12182 (2000); MEISEL, *supra* note 14, at 13-32.

¹⁴⁶ *In re Baby K*, 832 F. Supp. 1022, 1028 (E.D. Va. 1993) .

services, facilities, privileges, advantages, or accommodations being offered.¹⁴⁷ Therefore, Section 302 of the ADA carefully permits eligibility criteria for medical services to escape the definition of discrimination.

Mesiel and Cerminara report that “[a] physician’s medical assessment deeming treatment of a patient to be futile may be characterized as such an eligibility criterion” and thus would not seem to “constitute discrimination,” at least not on their face, without additional evidence that discriminatory motive was at work.¹⁴⁸ Furthermore, Meisel and Cerminara report that a Congressional committee has addressed the issue of eligibility criteria and that nothing in the ADA was intended to prohibit appropriate medical diagnosing.¹⁴⁹

Only the Child Abuse Amendments do not provide a private cause of action.¹⁵⁰ They only allow states that receive federal grants for child abuse and neglect to bring legal action through state child protective services agencies.¹⁵¹ Moreover, the Baby Doe amendments to the Child Abuse Amendments carry language to ensure that doctors would not be required to provide futile care.¹⁵² Under the Child Abuse

¹⁴⁷ Americans with Disabilities Act of 1990, 42 U.S.C. § 12182(b)(2)(A)(i) (2000).

¹⁴⁸ MEISEL, *supra* note 14, at 13-32;

Treatment decisions properly relate to the nature of the condition being treated. In deciding how to respond to a specific clinical situation, physicians consider the likely risks and benefits of different courses of action. A construction of the ADA that displaces bona fide medical decision-making altogether is at war with clinical medicine.

Nealy, *supra* note 135, at 146.

¹⁴⁹ MEISEL, *supra* note 14, at 13-32, 33.

¹⁵⁰ Nealy, *supra* note 135, at 147.

¹⁵¹ *Id.* at 147-48.

¹⁵² The bill enacted defined “withholding or medically indicated treatment” as:

[T]he term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician’s (or physicians’) reasonable medical judgment

Amendment, "a treatment should not be considered futile if it will definitely not prevent death in the near future."¹⁵³

Furthermore, several state advance directive statutes provide non-liability clauses for physicians who withhold or withdraw life-sustaining treatment based on their clinical judgment.¹⁵⁴ With one exception, these statutes provide little guidance in regards to the limiting of the obligation for physicians to provide ongoing care they believe futile.¹⁵⁵ Thus, the debate regarding futility and physician versus patient autonomy continues in the U.S.

B. The United Kingdom

"They know there is such a thing as a free lunch. Health care here in Britain is a banquet, and every bugger in this country thinks he's starving."¹⁵⁶

any of the following circumstances apply: (i) The infant is chronically and irreversibly comatose; (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (iii) The provisions of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

45 C.F.R. § 1340.15(b)(2) (2005).

¹⁵³ MEISEL, *supra* note 14, at 13-33.

¹⁵⁴ MEISEL, *supra* note 14 at 13-35. *See also*, CAL. PROB. CODE § 4735 (West 2005); DEL. CODE ANN. TIT. 16, § 2508(f) (2005); HAW. REV. STAT. § 327E-7(f) (2004); *See* Md. Op. Att'y Gen. No. 00-029 (Nov. 16, 2000) (construing Maryland's Health Care Decisions Act); ME. REV. STAT. ANN. TIT. 18A, § 5-807(F) (Weil, 2005); MISS. CODE ANN. § 41-41-215(6) (West 2005); NEV. STAT. ANN. § 449.670 (West 2004); N.J. STAT. ANN. § 26-2H-62(d) (West 2005); N.M. STAT. ANN. § 24-7A-7(F) (West 2005); TEX. HEALTH & SAFETY CODE ANN. § 166.046 (Vernon 2005).

¹⁵⁵ Mesiel, *supra* note 14, at § 13.07. Tex. Health & Safety Code § 166.046 (Vernon 2005) does provide a process-based approach to futility issues that will provide legal protection to physicians and facilities that follow the codified procedure. *See* discussion *infra* pp. 45-46.

¹⁵⁶ Eric G. Anderson, *Lessons America Should Learn From a Land of 'Free' Health Care*, *Managed Care*, (Jan. 1997),

In contrast to the U.S.'s free enterprise approach to medicine, the U.K. has incorporated a nationalized health service (NHS).¹⁵⁷ Following the devastation of World War II, Prime Minister Aneurin Bevan established the NHS on July 5th, 1948, so that the government could provide health services free of charge to the public.¹⁵⁸ Demand for medical treatment in the U.K. rapidly increased once the services became "free." Medical rationing and protracted time periods for health care were the norm.¹⁵⁹ In 1951, Bevan resigned from his position as Prime Minister in protest against the NHS introducing charges for dental care.¹⁶⁰ Just three years after its inception, one of the major issues that the NHS still struggles with today had surfaced: how to pay for nationalized health care.¹⁶¹

1. Withdrawing and Withholding Life-Prolonging Medical Treatment in the U.K.

Definitive case law regarding medical futility in the U.K. includes both *In re J* and *Airedale NHS Trust v. Bland*.¹⁶² Baby J suffered from cerebral palsy, microcephalia, blindness, and epilepsy as a result of a serious head injury suffered at the age of one month; J's life expectancy was short.¹⁶³ His physicians, whose view was supported by NHS and other medical opinion, considered the use of mechanical ventilation inappropriate.¹⁶⁴ The trial judge ordered that life-prolonging

<http://www.managedcaremag.com/archives/9701/9701.lessons.shtml> (last visited Mar. 24, 2006).

¹⁵⁷ *Id.*

¹⁵⁸ See Historic Figures, Aneurin Bevan, http://www.bbc.co.uk/history/historic_figures/bevan_aneurin.shtml (last visited Mar. 24, 2006).

¹⁵⁹ Donald Irvine, *The changing relationship between the public and the medical profession*, 94 J. R. SOC. MED. 162. (2001).

¹⁶⁰ Historic Figures, Aneurin Bevan, *supra* note 158.

¹⁶¹ See Irvine, *supra* note 159.

¹⁶² Richard Hamilton, *The Law on Dying*, 95 J. R. Soc. Med. 565 (2002); Brody & Gillon, *supra* note 20, at n. 2. See generally *In re J*, [1992] 3 W.L.R. 507 (Fam.), [1993] Fam. 15 (Eng.).

¹⁶³ *In re J*, *supra*, note 162.

¹⁶⁴ See *id.*

measures be applied pending further hearings.¹⁶⁵ On appeal, the court refused to require that J's physicians treat him if the physician's clinical judgment had determined that it was not in his patient's best interest, even if the patient's family wanted continued treatment.¹⁶⁶ "It is impracticable, and unlikely to be in the patient's best interests, to compel a doctor to exercise his skill in a specified manner against his professional judgment."¹⁶⁷

Airedale N.H.S. Trust Respondents v. Bland is the first U.K. case to address under what circumstances a physician can legally withdraw life-sustaining treatment, without which the patient would die.¹⁶⁸ Anthony Bland suffered injuries as a spectator at a soccer match which resulted in his PVS state.¹⁶⁹ Three years after the accident, the Airedale NHS Trust, with the support of Bland's parents, requested a declaration stating that withdrawal of artificial nutrition and hydration, ventilation, and further medical treatment would not be unlawful.¹⁷⁰ The House of Lords accepted that artificial nutrition and hydration, which they defined as a medical treatment, could lawfully be withdrawn on the basis of Bland's "best interest."¹⁷¹ The House of Lords further required that a declaration from the court must be obtained in PVS cases "that continued treatment and care no longer confer any benefit" before life-sustaining treatment is removed.¹⁷² *Bland* has been applied in several PVS and borderline PVS cases in the U.K.¹⁷³ In every instance, the courts have reported that in making a decision to withdraw life-sustaining treatment "it is not imposing death but is, rather, not taking any steps to prolong life."¹⁷⁴ The British Medical Association (BMA) published guidelines regarding the withholding or withdrawing of treatment in 1999, identifying other non-beneficial treatments that courts need not review

¹⁶⁵ *Id.*

¹⁶⁶ *Id.*

¹⁶⁷ *Id.* at 4.

¹⁶⁸ *Airedale N.H.S. Trust Respondents v. Bland* [1993] A.C. 789, 797 (Eng.).

¹⁶⁹ *Id.*

¹⁷⁰ *Id.* at 789.

¹⁷¹ *Id.* at 896-899.

¹⁷² *Id.* at 789.

¹⁷³ *Id.*

¹⁷⁴ Hamilton, *supra* note 162, at 565.

for physicians to terminate treatment.¹⁷⁵ Thus, physician autonomy and “benefiting the patient” by not prolonging life have been paramount concerns in the U.K. from which the courts have ruled for the discontinuance of non-beneficial care.

Furthermore, both the General Medical Counsel (GMC) and the BMA have issued guidelines that allow for the withdrawal of treatment “when it is futile in that it cannot accomplish any improvement, when it would not be in the patient's best interest to continue treatment (because, for example, it is simply prolonging the dying process) or when the patient has refused further treatment.”¹⁷⁶

The GMC is a statutory body established under the Medical Act of 1858 to “protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine.”¹⁷⁷ The Medical Act authorizes the GMC to license physicians to practice in the U.K.¹⁷⁸ The guidance provided by the GMC for physicians on withholding and withdrawing futile care¹⁷⁹ creates no statutory legal obligation, although courts have reviewed its guidance in court decisions.¹⁸⁰

¹⁷⁵ Laurence Oates, *The Courts' Role in Decisions about Medical Treatment*, 321 BRIT. MED. J. 1282 (2000). For further discussion regarding the British Medical Association see *infra* pp. note 181.

¹⁷⁶ End of Life Decisions – Views of the BMA, at <http://www.bma.org.uk/ap.nsf/Content/Endoflife> (last visited Mar. 27, 2006).

¹⁷⁷ Role of the GMC [General Medical Counsel], at <http://www.gmc-uk.org/about/role/index.asp> (last visited Mar. 27, 2006).

¹⁷⁸ *Id.*

¹⁷⁹ General Medical Council, Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-Making (2002), at http://www.gmc-uk.org/guidance/library/standards/withholding_lifeprolonging_guidance.asp (last visited Mar. 27, 2006).

¹⁸⁰ UK Clinical Ethics Network Section D. Professional Guidelines, Law and Ethics, at <http://www.ethics-network.org.uk/reading/Guide/SectionD/sectionD.htm> (last visited Mar. 27, 2006).

The BMA is a voluntary association of physicians, with a total membership of over 137,000, including over 19,000 medical students.¹⁸¹ The BMA produces numerous publications regarding ethical issues including, *Withholding and Withdrawing Life-Prolonging Medical Treatment: Guidance for Decision Making*, which like the GMC's guidelines are not legally binding, but can be taken into account by the courts in addressing specific cases.¹⁸²

2. The Human Rights Act of 1998

The Human Rights Act (1998) came into effect October 2, 2000 in the U.K. It incorporates the European Convention on Human Rights and Fundamental Freedoms into U.K. domestic law. The main purpose of the Convention "is to safeguard human rights and fundamental freedoms and to maintain and promote the values of a democratic society."¹⁸³

Any inconsistency between current U.K. legislation and the Convention can be challenged in domestic courts and also in the European Court of Human Rights. Furthermore, public authorities (e.g. the NHS Trust, doctors) must comply with the Convention's guidelines for medical care.¹⁸⁴

The Articles of the Convention that have had major impact on healthcare are Article 2 (the right to life), 3 (the prohibition on torture and inhuman or degrading treatment), 5 (the right to liberty and security), and 8 (the right to respect for private and family life). None of these rights is absolute but Article 3 represents an absolute prohibition and cannot be interfered with by the State under any circumstances. Article 2

¹⁸¹ BMA [British Medical Association], About the BMA, <http://www.bma.org.uk/ap.nsf/Content/Hubaboutthebma> (last visited Mar. 24, 2006).

¹⁸² UK Clinical Ethics, *supra* note 172.

¹⁸³ Ash Samanta & Jo Samanta, *The Human Rights Act 1998 – Why Should it Matter for Medical Practice?*, 98 J. R. SOC. MED. 404 (2005).

¹⁸⁴ Department of Health – Human Rights Act 1998 FAQ, http://www.dh.gov.uk/PolicyAndGuidance/EqualityAndHumanRights/EqualityAndHumanRightsArticle/fs/en?CONTENT_ID=4054183&chk=QOxVM9 (last visited Mar. 27, 2006).

and 5 are subject to limited exceptions. Article 8 is a qualified obligation that requires a balance to be struck between the interests of the individual and the wider interests of society. Any limitation or constraint imposed by a public body must be justified as being 'proportionate to the legitimate aim pursued'.¹⁸⁵

ECHR guidelines will have a lasting effect on the healthcare practices in the U.K. The ECHR has been actively involved in issues regarding life and death (e.g., withholding or withdrawing life-sustaining treatment).¹⁸⁶ Article 2 has been interpreted by U.K. courts to as containing a negative right to not intentionally and illegally take a life.¹⁸⁷ In *Re A*, "[t]he Court of Appeals took the view that Article 2 imposed a duty to protect the stronger twin and not just a negative duty of preventing death for the weaker twin."¹⁸⁸ The surgery to separate the twins was justified by saving the life of the stronger twin and not "intentionally" taking the life of the weaker twin.¹⁸⁹ Furthermore, Article

¹⁸⁵ Samanta & Samanta, *supra* note 183.

¹⁸⁶ *Id.* at 405.

¹⁸⁷ *Id.*

¹⁸⁸ *Id.* at 405.

¹⁸⁹ Rationale behind the decision:

[The purpose of the application] was to preserve the life of J and not to cause the death of M, it was inappropriate in the unique circumstances to characterise foresight of M's accelerated death as amounting to criminal intent; that the protection of a person's right to life in article 2 of the Convention for the Protection of Human Rights and Fundamental Freedoms did not import any prohibition, additional to that under English common law, to the proposed operation, and "intentionally" in its ordinary and natural meaning applied only to cases where the purpose of the prohibited action was to cause death; that (per Ward LJ) in essence there was no difference between resorting to legitimate self-defence and the doctors coming to J's defence and removing the threat of fatal harm to her presented by M's draining her lifeblood; and that, accordingly, the operation could be lawfully carried out.

In re A, [2001] Fam 147, 2000 WL 1274054 (CA (Civ Div)).

2's negative right has been interpreted to authorize the continued removal of artificial hydration and nutrition because, the illness, not the treatment (artificial nutrition and hydration), would be the cause of the patient's death.

Additionally, withholding and withdrawing life-sustaining treatment would not violate Article 3 if doing so would be in the patient's best interest.¹⁹⁰ But Article 3 has been interpreted to allow courts, not physicians to determine the patient's "best interest" where there are disputes about proposed treatment for incompetent patients.¹⁹¹

However, the confusion surrounding the ECHR in U.K. court systems continues as represented by the case of Leslie Burke.¹⁹² Mr. Burke, who suffered from a degenerative brain condition, was afraid that artificial nutrition and hydration could be withdrawn against his wishes according to the GMC's "*Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-Making*" guidelines.¹⁹³ The High Court ruled that GMC's guidance was in violation of Articles 3 and 8 of the Human Rights Act of 1998. The Honourable Mr. Justice Munby ruled that not only do patients have a right to demand the withdrawal of life-sustaining treatment, but they also have a positive right to demand treatment in certain circumstances. Judge Munby acknowledged that in addressing this ethical issue, further important issues of limited resources are involved.¹⁹⁴

On appeal by the GMC, the Court of Appeal ruled that Mr. Burkes' concerns were adequately addressed by the GMC's guidelines regarding withholding and withdrawing life-prolonging treatment.¹⁹⁵ The Court of Appeal held that physicians cannot deny competent patients

¹⁹⁰ Samanta & Samanta, *supra* note 183, at 405.

¹⁹¹ *Id.* at 406.

¹⁹² See BBC News, *Patient Wins Right-to-Life Ruling*, <http://news.bbc.co.uk/1/hi/health/3938879.stm> (last visited Mar. 27, 2006); BBC News, *Patient Loses Right-to-Food Case*, *supra* note 37.

¹⁹³ Tom Woodcock & Robert Wheeler, *Glass v United Kingdom and Burke v General Medical Council. Judicial interpretation of European Convention Rights for patients in the United Kingdom Facing Decisions about Life-Sustaining Treatment*, 31 INTENSIVE CARE MED. 885 (2005).

¹⁹⁴ *Id.*

¹⁹⁵ BBC News, *Patient Loses Right-to-Food Case*, *supra* note 37.

artificial nutrition or hydration, unless during the final stages of their illnesses artificial nutrition and hydration could not prolong their lives.¹⁹⁶ Thus, artificial nutrition and hydration can be withdrawn from Mr. Burke only during the end stages of his illness when he lapses into a coma; when he can no longer express his desire for life-prolonging treatment.¹⁹⁷

IV. Communicating Past the Conflict

The basic problem with futility is that the clinical reality of the uniqueness of patients and diseases results in judgments of futility that are not easily formulated into a general substantive definition.¹⁹⁸

Futility is a value laden judgment; it should be seen as unique to each patient and family, and thus a universal consensus regarding futile care is unlikely. Rather than relying on a definitive definition of futility, several organizations have moved towards recommending a process that would allow a thorough review of the futility dispute in a fair and open environment that requires communication between patients and their families, doctors, and facilities.¹⁹⁹

Failure to communicate about diagnosis and prognosis often causes increased discord amongst patients, families, and physicians;²⁰⁰ this lack of communication may ultimately lead to the courtroom.²⁰¹ Establishing effective communication standards between patients, their families, and physicians leads to mutual understanding regarding

¹⁹⁶ Clare Dyer, *Court rules in favour of GMC's guidance on withholding treatment*, 331 BRIT. MED. J. 309 (2005) (The GMC's president Graeme Catto said, "[o]ur guidance makes it clear that patients should never be discriminated against on the grounds of disability. And we have always said that causing patients to die from and dehydration is unacceptable practice and unlawful.").

¹⁹⁷ *Id.*

¹⁹⁸ Amir Halevy & Baruch A. Brody, *A Multi-institution Collaborative Policy on Medical Futility*, 276 J. AM. MED. ASSOC. 571, 571 (1996).

¹⁹⁹ *Id.* at 574.

²⁰⁰ Fins, *supra* note 48, at 1322.

²⁰¹ In the Matter of Baby "K", 832 F. Supp. 1022 (E.D. Va. 1993); Woodcock & Wheeler, *supra* note 178.

treatment goals.²⁰² Furthermore, process-based approaches to futile care may even provide legal protection for physicians or facilities' decisions to withdraw non-beneficial care against the desires of patients or families.²⁰³

A. Moving Towards a Process-Based Approach

Recognizing the "futility" of attempting to define futile care, several health care organizations started defining a process to address the issue of futile care with patients and their families.²⁰⁴ These policies were developed to provide physicians, patients, and their families with an avenue to collaboratively approach the futility decision. This approach allowed the definition of futility to be moved away from one physician or hospital treatment team to a facility ethics committee. This approach may also provided the opportunity to create a community-wide approach to futility, while respecting the input of the patient or family.²⁰⁵

One of the earliest process-based approaches created was the Houston (Texas) policy.²⁰⁶ The Houston policy was a collaborative effort of a diverse task force which included most of Houston, Texas' hospitals. The Houston policy allowed a patient to transfer to another physician or facility if no resolution could be reached. However, if another physician or facility would not accept the transfer, the attending physician or facility would not be responsible for continued futile care.

²⁰² "[Ethics] consultations were associated with reduced hospital stays and treatment costs and were deemed effective in resolving conflicts that were blocking the way of more appropriate comfort care." Gilmer et al., *supra* note 35, at 967.

²⁰³ See generally, TEX. HEALTH & SAFETY CODE ANN. § 166.046 (Vernon 2003).

²⁰⁴ See generally, Health Council of South Florida, *supra* note 3, at 30-44.

²⁰⁵ American Medical Association, *Medical Futility in End-of-Life Care*, CEJA Op. 2.037 (June 1997), available at <http://www.ama-assn.org/ama/pub/category/8390.html>

²⁰⁶ A committee was formed in August of 1993 with representation from most of the major Houston hospitals. After two years, "Guidelines on Institutional Policies on the Determination of Medically Inappropriate Interventions" were presented for institutional approval at the various Houston hospitals. Halevy & Brody, *supra* note 198, at 571.

Regardless of transfer options, the policy stated that patient abandonment is prohibited. Only interventions that are deemed non-beneficial could be ceased; other care that preserved the comfort and dignity of the patient must be continued.²⁰⁷

In 1999, the American Medical Association Council on Ethical and Judicial Affairs published its recommendation for a due process-based approach to futility determinations in the *Journal of the American Medical Association (JAMA)*.²⁰⁸

The process includes at least 4 steps aimed at deliberation and resolution including all involved parties [physicians, patient, and family], 2 steps aimed at securing alternatives and resolutions including all involved parties, 2 steps aimed at securing alternatives in the case of irreconcilable differences, and a final step aimed at closure when all alternatives have been exhausted.²⁰⁹

Recognizing that there are “necessary value judgments involved in coming to the assessment of futility,” the American Medical Association’s (AMA) process requires that futility judgments account for patients’ or proxies’ input.²¹⁰

This process utilizes the same procedures that hospital ethics committees have been using for years, with attempts to transfer the patient if a mutual agreement could not be reached regarding the patient’s continued care.²¹¹ If no alternative provider can be found, the Council’s guidance allows the futile intervention to be discontinued (that is, as determined by the process involving the patient/proxy, physicians, and institutional committee).

²⁰⁷ *Id.* at 572-73.

²⁰⁸ American Medical Association, *supra* note 15, at 939.

²⁰⁹ *Id.*

²¹⁰ *Id.*

²¹¹ Robert L. Fine, *Medical Futility and the Texas Advance Directives Act of 1999*, 13 BAYLOR U. MED. CENTER PROC. 144 (2000), available at http://www.baylorhealth.edu/proceedings/13_2/13_2_fine.html.

Legal considerations are of paramount concern when discussing the discontinuation of care. Although no formal recognition of a “positive” right to demand treatment has taken place, patient autonomy for healthcare decisions must be carefully balanced against physicians’ autonomy to make clinical decisions.²¹² Litigation regarding futility has remained constant, but limited, since the early 1990s.²¹³ Having set forth their policy, the AMA did note legal ramifications of withholding treatment are unknown.²¹⁴ One case in the U.S. that has found in favor of physician autonomy to withhold non-beneficial care is *Gilgunn v. Massachusetts General Hospital*.²¹⁵ This case involves a physician ordering a do-not-resuscitate (DNR) order without the family’s consent.²¹⁶ After the patient died, the family sued the hospital and physician.²¹⁷ The jury ruled in favor of the physician and hospital.²¹⁸ Yet this case is not precedent setting because the reasons for the jury finding for the defendants was not recorded.²¹⁹

Even with legal protection unknown, process based approaches to futility issues provide benefits to both physicians and facilities. They can provide treatment clarity and assist with a transition from a curative to a palliative model free from conflict between patient, families, and facilities.²²⁰ Furthermore, one recent study regarding ethics consults in the intensive care unit reported “that ethics consultations reduced hospital spending and hastened death among those who ultimately die in

²¹² MEISEL, *supra* note 14 at § 13.02.

²¹³ *Id.* at 13-5.

²¹⁴ American Medical Association, *supra* note 15.

²¹⁵ John Ellement, *Jury Sides with Doctors on Ending Woman’s Life Support*, BOSTON GLOBE, Apr. 22, 1995, at 18.

²¹⁶ *Id.*

²¹⁷ *Id.*

²¹⁸ *Id.*

²¹⁹ Stanley A. Nasraway, *Unilateral withdrawal of life-sustaining therapy: Is it time?*, 29 CRIT. CARE MED. 215 (2001), available at http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11200242&dopt=Abstract.

²²⁰ Robert L. Fine & Thomas W. Mayo, *Resolution of Futility by Due Process: Early Experience with the Texas Advance Directive Act*, 138 ANNALS INTERNAL MED., 743, 744-745 (2003).

[the] hospital after a prolonged stay.”²²¹ In follow-up interviews with nurses, physicians, and patients, more than 90 percent of the health care professionals and 80 percent of patients or proxies agreed that ethics consultations were useful in determining appropriate treatment.²²²

In the U.K., the Human Rights Act 1998 requires that physicians must consult with patients and their families in making treatment decisions.²²³ Additionally, beginning in April 2002, each NHS in the U.K. is required to have Patient Advocacy and Liaison Services (PALS) advocates to assist patients and families with medical decisions.²²⁴ The implementation of PALS advocates recognizes the need for the inclusion of the patient's view in determination of treatment decisions, even though U.K. courts, unlike the U.S. courts, generally side with the decisions of the physicians regarding issues of withdrawing or withholding futile care.²²⁵

B. Legalizing the Withholding or Withdrawal of Futile Care in the U.S.

One state does recognize the ability for physicians and facilities to withhold or withdraw futile care. The Texas Advanced Directives Act of 1999 not only combined several laws dealing with end-of-life decisions into a single statute, it provided a due-process approach to futile care which provides legal protection to physicians and facilities that follow the statutory guideline.²²⁶ This statute, an evolution of the Houston policy, was enacted into Texas law shortly after the American

²²¹ Gilmer et al., *supra* note 35, at 969.

²²² *Id.*

²²³ Abhay K. Das, *The Value of an Ethics History?*, 98 J. R.. SOC. MED. 262 (2005).

²²⁴ Kay Lurie, *Withholding and Withdrawing Life-Prolonging Treatments: Good Practice In Decision-Making The Role of the Patient's Advocate*, Barnet Community Health Council, (June 20, 2001), at <http://www.barnetchc.org.uk/scrutiny/withholding.htm> (last visited Mar. 25, 2006).

²²⁵ *Id.*

²²⁶ Fine, *supra* note 211; *See also*, TEX. HEALTH & SAFETY CODE ANN. § 166.046 (Vernon 2003).

Medical Association published their medical futility in end-of-life care policy.²²⁷

Fine and Mayo in *Resolutions of Futility by Due Process: Early Experiences with the Texas Advance Directives Acts* state:

[T]he greatest significance of the law is how it changes the nature of conversations between providers and patients' families about futile-treatment situations by providing conceptual and temporal boundaries. ...[I]t places limits on families and surrogates who request therapies that the profession consider futile. At the same time, it forces the profession to think carefully about the concept, for if another physician and facility are willing to provide the futile treatment, then the law does not allow withdrawal of that treatment on grounds of futility. The law also provides temporal boundaries (12 days) for resolving disagreements over futile treatment.²²⁸

They further encourage other states to look at the Texas futile care process as a starting point for possible changes in statutory regulation regarding medical futility.²²⁹

CONCLUSION

"Futility" is a value-laden concept that escapes definition. Physicians, healthcare facilities, and patients in the U.S. and U.K. have struggled with end-of-life decisions regarding futile care due to the lack of a definitive definition of futility. These struggles have often ended up in the legal system, moving the decision of appropriate medical care away from the physicians or family to the discretion of a judge or jury. With the ever-increasing cost of health care and the explosion of medical technology, the struggle to differentiate appropriate care from futile care will continue, increasing conflict among health care

²²⁷ Telephone Interview with Professor Tom Mayo, Director, Cary M. Maguire Center for Ethics and Public Responsibility, SMU, Tex. (Oct. 20, 2005).

²²⁸ Fine & Mayo, *supra* note 220, at 746.

²²⁹ *Id.*

facilities, physicians, and families with patient's continued care caught in the balance.²³⁰

Instead of focusing on defining futile scenarios, physicians and healthcare facilities should focus on providing appropriate communication to assist the patient and family in making end-of-life decisions. This process-based approach to futile care will establish appropriate boundaries for patients and families to address the issue of appropriate care by providing a process in which they can communicate with health care professionals, as well as establish collaborative goals for treatment after treatment options are reviewed. Furthermore, this collaborative approach will decrease the conflict between physicians and patients, leading to a decrease in overall healthcare cost and patient/physician satisfaction.

By providing the ability for patient transfer, process-based approaches will open the definition of "futility" to a community-wide standard, making healthcare professionals think very carefully about deeming a treatment futile, because acceptance of transfer will prevent the removal of treatment on the grounds of futility.²³¹

Withdrawal of treatment is a treatment of last resort; whether made by a patient, physician, or a patient's family, the decision deeming care futile should only be determined after careful deliberation and consultation with all appropriate parties. Clearly, defined processed-based approaches should provide the opportunity for collaboration of physicians, families, and patients, thus allowing the patient's best interest to determine treatment (whether it is palliative care or continued treatment for the illness at hand).

²³⁰ See generally, Gilmer et al., *supra* note 35 (surveying the increasing cost of health care in today's world).

²³¹ Fine & Mayo, *supra* 220, at 746.