

FUTILITY AND MEDICAL PROFESSIONALISM†

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The medical futility debate is a fascinating mirror of the changing relationship between society and the profession and practice of medicine. I define the "medical futility" debate to be about the medical prerogative to conclude that a treatment is so unlikely to be beneficial or its benefits are such a stark departure from the normative ends of healing, palliating, or rehabilitating medicine that a physician is not obliged to offer or prescribe the treatment.¹ The recent intensity of the debate about futility has partly obscured the longer history of this ethic. That history illuminates the merits and problems of this idea and shows how the social context of medicine supported the social construction of a futility ethic for medical professionalism.

I. A BRIEF RECENT HISTORY OF MEDICAL FUTILITY

The first phase of futility ethics in American medical professionalism might be called "Hippocratic-paternalism." This phase consisted of two partly related phenomena. First, a longstanding tradition of paternalistic silence existed concerning disclosure of bad diagnoses to patients and procurement of patients' informed choice of, and consent to, therapies. A professional consensus to curtail life-prolonging efforts for persons at the end of life also existed. This sense of professional limits at the end of life has classical roots and lasted until the mid-1960s.² Despite the disadvantage of silence in the doctor-patient relationship, futility implicitly provided a case by case framework for acknowledging the limits of medical care, partly because of an incomplete science, and funda-

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¹ This definition focuses on the scope of the health provider's discretionary duty and prerogatives because it is established that patients may themselves decline to demand or accept any therapy they want regardless of whether such therapy is futile or their condition is reversible.

² Darrel W. Amundsen, *The Physician's Obligation to Prolong Life: A Medical Duty without Classical Roots*, HASTINGS CENTER REP., Aug. 1978, at 23-30; Nancy S. Jecker, *Knowing When to Stop: The Limits of Medicine*, HASTINGS CENTER REP., May-June 1991, at 5-8.

mentally because of human mortality.³ The medical ethic of futility offered a consoling way to speak of the limits of medical effort, not as abandonment, but as acknowledgement of the imminent necessary deference to mortality at deathbed scenes that were increasingly played out on a medical stage.

The second phase, a *pax futilis*, lasted from the early 1960s to the late 1980s. This phase was characterized by increasing societal and professional respect for informed consent and a tidal shift in providing bad news to patients. Even so, reticence continued about widely practiced clinical decisions to withhold futile treatment, through the use of phrases such as, "He is not a surgical candidate" or "She is hopelessly ill."

Several events during the *pax futilis* are worth noting. This phase began soon after cardio-pulmonary resuscitation (CPR) was introduced in the 1960s, when it was recognized that CPR had to be automatically provided to be effective. The *universal* provision of CPR contradicted standard *individualized* practice of not employing heroic therapies on persons at the end of life. All of the periodically published national practice guidelines for CPR have contained explicit futility exceptions to routine CPR.⁴ In the mid-1970s, the right-to-die movement resulted in formal recognition of the patient's right to decline CPR in those same standards.⁵ This use of futility allowed individualization of care, selectively allocating CPR to patients with non-terminal conditions for whom this therapy would work.

During the *pax futilis*, conceptual work on futility occurred through a low key debate. Major medical ethics tracts⁶ usually said

³ SHERWIN B. NULAND, *HOW WE DIE: REFLECTIONS ON LIFE'S FINAL CHAPTER* 244-46 (1994).

⁴ For example, the 1974 standards proposed that CPR be used "in any situation where it is medically indicated," noting that "terminal irreversible illness where death is not unexpected" were examples of situations where it was not indicated. National Conference Steering Committee, *Standards for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)*, 227 JAMA 837, 864 (1974). Subsequent standards further codified futility adding decapitation, rigor mortis, and injuries incompatible with life. The most recent standard defines futile as consisting of either a failed trial of CPR and CPR in circumstances in which CPR has been empirically shown not to work. See Emergency Cardiac Care Committee and Subcommittees, American Heart Association, *Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiac Care: Ethical Principles and Guidelines*, 268 JAMA 2282 (1992).

⁵ One of the earliest models of do-not-resuscitate (DNR) policies from the early 1980s banned DNR orders if a patient did not consent because of uncertainty about the legal foundation of writing a DNR order that a patient did not consent to. STEVEN H. MILES & CARLOS F. GOMEZ, *PROTOCOLS FOR ELECTIVE USE OF LIFE SUSTAINING TREATMENTS* 5-6, 78 (1989).

⁶ PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND

that physicians were not obliged to provide futile therapies but did not rigorously define futility or its implications for patient autonomy.⁷ Early controversies about the application of "futility" to non-dying, conscious, disabled persons (e.g. minor surgery to enable persons with Down's Syndrome to eat food or to prevent persons paralyzed by congenital spinal cord abnormalities from dying of infection) established that futility could not be applied to such classes of persons. One widely discussed paper proposed that a patient need not be told of the option of a widely used therapy like CPR that was being withheld on the grounds of futility;⁸ the resulting consensus quickly favored disclosure even absent an obligation to treat. This discussion, however, was not a full scale medical or ethics discussion about how to define futility or how to arbitrate what would become known as "futility disputes." For ethicists and clinicians alike, this silence obscured the degree to which respect for patients' autonomy in refusing a recommended "indicated" therapy, or in choosing the best of all medically indicated therapies, became a movement in which patient-defined goals for medicine supplanted professional norms upon which medical indications (and futility) were founded.

The *pax futilis* ended with the Wanglie case in 1991.⁹ Wanglie was an eighty-six year old woman who was respirator dependent from lung disease before suffering a cardiac arrest that rendered her permanently unconscious. The hospital staff did not want to provide the continued intensive care requested by the husband, and unsuccessfully sought to clarify its duty to do so. The ensuing debate spotlighted the lack of social consensus on an explicit definition of futility, on rules for clinicians to act on such a concept if it did exist, and on the manner by which such a consensus could be drafted.

The current phase of the futility debate, "relativised futility,"

BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 240 (1983); HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING 32 (David H. Smith & Robert M. Veach eds. 1987).

⁷ The major exception was the successful construction of "brain death" as a legal and ethical definition for unilaterally discontinuing therapy or harvesting organs from a person on life support by declaring them dead. Many ethicists feel that it would be difficult to create such a concept today.

⁸ See Leslie J. Blackhall, *Must We Always Use CPR?*, 317 NEW ENG. J. MED. 1281 (1987).

⁹ See Steven H. Miles, *Informed Demand for "Non-Beneficial" Medical Treatment*, 325 NEW ENG. J. MED. 512 (1991); Marcia Angell, *The Case of Helga Wanglie: A New Kind of "Right to Die" Case*, 325 NEW ENG. J. MED. 511 (1991).

has been a cacophony of proposals and intense disagreement. Many bioethicists seemed surprised and upset by resurgent clinical interest in futility ethics. One bioethicist called it the "problem without a name,"¹⁰ another asserted that the idea sets bioethics "back twenty years" to a silent paternalism. Veatch and Spicer made the most extreme claim: citing respect for patient autonomy in decisions to refuse care, they maintained that absent a statutory or insurance contract definition of the term, futility should be confined to rare cases when the requested therapies had no physiologic effect.¹¹ Other commentators argued that prominent public cases in which the contested therapy would only briefly prolong life in a dying person, prolong life of permanently unconscious persons, or have an extremely tiny (but not absolute zero) benefit, should be an area for patient choice rather than professional discretion.¹² Early case law has been critical of medical futility, finding several reasons to assert that patients have authority over decisions to stop life in disputes that are adjudicated before life support is discontinued.¹³

¹⁰ Daniel Callahan, *Medical Futility, Medical Necessity: The Problem-Without-A-Name*, HASTINGS CENTER REP. July 1991, at 30-35.

¹¹ Robert M. Veatch & Carol M. Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 AM. J.L. & MED. 15 (1992).

¹² See Dan W. Brock & Steven A. Wartman, *When Competent Patients Make Irrational Choices*, 322 NEW ENG. J. MED. 1595 (1990); Robert D. Truog et al., *The Problem With Futility*, 326 NEW ENG. J. MED. 1560 (1992); Allan S. Brett & Laurence B. McCullough, *When Patients Request Specific Interventions: Defining the Limits of the Physician's Obligation*, 315 NEW ENG. J. MED. 1347 (1986).

¹³ In New Jersey, statutes allow a religious dissent to brain death. See Robert S. Olick, *Brain Death, Religious Freedom, and Public Policy: New Jersey's Landmark Legislative Initiative*, 1 KENNEDY INST. ETHICS J. 275, 275-92 (1991) (discussing the New Jersey Declaration of Death Act's recognition of a religious exemption to respect the religious beliefs of persons who do not base the determination of death on neurological criteria). For a discussion of court cases that have allowed a brain dead woman to stay on dialysis, see Michael A. Nevins, *It's Time to Get Serious About Defining Futility*, TRENDS HEALTH CARE, L. & ETHICS, Winter 1994, at 31-36; Lisa Belkin, *As Family Protests, Hospital Sees the End to a Woman's Life Support*, N.Y. TIMES, Jan. 10, 1991, at A1; see also L. Ross, *Family Says Treatment Withheld*, FLA. TIMES UNION, May 23, 1991, at A1-A2 (discussing cases allowing continued treatment on dying persons and adults); Alexander Reid, *After Transplant, A Fight Over Care*, BOSTON GLOBE, June 23, 1991, at A21, A23 (discussing a case allowing continued treatment on a comatose adult). A federal court of appeals recently affirmed a decision requiring a hospital to indefinitely prolonged respirator for an anencephalic baby under the Emergency Medical Treatment Act. *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

It is important to note the limited framing of the cases adjudicated to date. These cases have not examined whether a clinician could be sued or prosecuted for failing to start therapy, to perform surgery, or to provide CPR that the treating clinician on the basis of well-conducted research finds to be demonstrably futile. They

Other bioethicists, who strike me as somewhat more likely to have clinical experience and duties, have developed a taxonomy of futility, including quantitative futility (in which the likelihood of effect is small), or qualitative futility (in which an outcome such as death before hospital discharge or sustained permanent unconscious life is not worth a medical effort).¹⁴ A number of hospitals, medical societies, and, more recently, groups of hospitals have explored or published policies defining futility or procedures for handling disputes. These newer health facility policies have not been tested in court.

II. FUTILITY AND SOCIAL CONTEXT

The foregoing review illustrates that futility has been defined in a historical context. In various settings, futility has served to acknowledge the necessity of aggressive medical science (that had presumed to displace clergy at the death bed) to withdraw, not abandon, in the face of an essential human mortality. Futility has individualized treatment plans, keeping the patients' specific medical condition and personhood in the foreground, as evidenced by a new CPR policy suggesting that the unifactorial event of cardiac arrest is the indication for CPR. The future of futility, like other concepts used to mediate balanced interests and responsibilities in the legal and medical professions, will also be historically and contextually defined.¹⁵ Ethicists or lawyers who demand a context-free

have also not clarified whether a physician would be found liable of malpractice *after* having stopped a therapy that the physician believed to be nonbeneficial.

¹⁴ See, e.g., Kathy Faber-Langendoen, *Resuscitation of Patients with Metastatic Cancer: Is Transient Benefit Still Futile?*, 151 ARCHIVES INTERNAL MED. 235 (1991); Donald J. Murphy, *Do-Not-Resuscitate Orders: Time for Reappraisal in Long-Term-Care Institutions*, 260 JAMA 2098 (1988); John J. Paris et al., *Physicians' Refusal of Requested Treatment: The Case of Baby L*, 322 NEW ENG. J. MED. 1012 (1990); Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949 (1990); George E. Taffett et al., *In-Hospital Cardiopulmonary Resuscitation*, 260 JAMA 2069 (1988); Tom Tomlinson & Howard Brody, *Futility and the Ethics of Resuscitation*, 264 JAMA 1276 (1990); Stuart J. Youngner, *Futility in Context*, 264 JAMA 1295 (1990).

Health professional association statements include: Council on Ethical and Judicial Affairs, American Medical Association, *Guidelines for the Appropriate Use of Do-not-resuscitate Orders*, 265 JAMA 1868 (1991); American Thoracic Society, *Withholding and Withdrawing Life-sustaining Therapy*, 115 ANNALS INTERNAL MEDICINE 478 (1991); Task Force on Ethics, Society of Critical Care Medicine, *Consensus Report on the Ethics of Foregoing Life-sustaining Treatments in the Critically Ill*, 18 CRITICAL CARE MED. 1435 (1990).

¹⁵ In that futility is a concept that mediates the relative discretion of patients and providers, numerous commentators have pointed out that many futility disputes arise from failed or improperly conducted physician-patient discussions. Such discussions can fail for a variety of reasons: patients or families may enter the discussion with well founded mistrust of providers; providers may be insensitive, abrupt, and not allow

or purely logical futility as a precondition for using this term in health policy are imposing a burden on this term that we do not ask of other mediating concepts like standard of care, due process, or fiduciary responsibility. The imposition of that burden would lead to deconstructing and abandoning the concept.

The foregoing review also implies that the future of futility will evolve with the American health care system. Notwithstanding the health care reform debate of this past year, I believe that the case for universal health care has been made and is being slowly extended. The emerging American health care system will be one in which providers will deliver comprehensive health care to a defined population on a budget.¹⁶ Among the policies necessary to create this accountability will be a description of the health care services to be provided and more stringently defined terms to police that entitlement. Society will try to more precisely define or empower commonly used terms like "standard of care," "medically necessary," "medically appropriate,"¹⁷ "experimental therapy," and "medical futility."

Some propose supplanting clinical medical futility with an explicit codification of services to be universally offered. For example, society might attempt to legislatively describe specific coverage exclusions for respirators for anencephalic babies or permanently unconscious persons, CPR to persons with metastatic cancers, except for the skin cancer of melanoma, and so on. Such an approach is not workable for several reasons.¹⁸

families sufficient time to accommodate to catastrophic illness; and unresolved antecedent conflicts that have little to do with the futile care issue may polarize patients and providers. All of these are true, and justify substantial training and consultation in the course of clinical disputes. Even so, attributing futility disputes simply to poor counseling skills either begs the question, imputes powers to counseling skills that physicians do not have, or diminishes the reality of sincerely held differences of opinion in futile care disputes.

¹⁶ I do not here take any position on whether managed competition, sickness funds, national health service, or single payer with a budgeted restrictive infrastructure allocations are the specific means by which we will or should arrive at affordable universal health care. Rather, I simply want to suggest that any conclusion to the health care reform debate will embody the elements of accountability of the health care delivery system to a budget and a population.

¹⁷ Dan Callahan has pointed out the relation of futility to the debate about these common insurance terms. See Daniel Callahan, *Necessity, Futility, and the Good Society*, 42 J. AM. GERIATRIC SOC'Y 866 (1994).

¹⁸ Derek Bok attributes legal proposals for unworkable, complex regulatory policies to the failure of interdisciplinary education of lawyers and a tendency to focus on the immediate case at hand while paying less attention to its greater effects on the wider public. Judges and lawmakers, according to Bok,

need to search for a new understanding that is no less sensitive to injus-

First, there is no system of technology assessment that is foreseeably capable of prospectively defining successful or unsuccessful outcomes of all therapies in all individual circumstances. Health care entitlement codes to limit futile care and rules such as "no respirators for persons over 85," however appropriate as general rules, will be self-evidently wrong in many individual circumstances. Those individual cases will surface in the public debate to discredit the rules and the universal allocation code.

Second, no public body is capable of responding in a timely manner to appeals or changes in research favoring new treatments for previously deemed incurable conditions or demonstrating the disutility of accepted therapies.

Third, it is not possible to envision, and thus equitably provide for, all the potential claims for futile therapies that exist or might come to exist. Pregnant women who are brain dead have been appropriately maintained in intensive care units for months until fetal viability, despite a general rule that life support is stopped when a person is declared dead. Until Baby K, no one dreamed of using a respirator to support the growth of an anencephalic child.

Finally, no democratic political body is capable of enacting an explicit health care entitlement list. The codification of who is not to be sustained, however necessary or reasonable, would be socially destructive in its statement of which life had value and which life did not. Professor Calabresi makes a compelling argument why this is not done in rules for the death penalty, organ transplant priorities, and rationing. His astute dissection of social policies of tragic choices concludes that society can only create a general entitlement, admit the public need for tragic choices, and grant discretionary authority to decision makers who are somewhat removed

tice but more realistic in accounting for the limits and costs of legal rules in ordering human affairs. . . . Lacking such a vision, judges and regulators will continue to drift toward a general willingness to intervene when they feel that one person has suffered at the hands of another. That is the logical end of process that concentrates so heavily on the plight of individual litigants and gives so little heed to the effects on the system as a whole. What emerges from this process is a spurious form of justice. In such a world, the law may seem enlightened and humane but its constant stream of rules will leave a wake strewn with the disappointed hopes of those who find the legal system too complicated to understand, too quixotic to command respect, and too expensive to be of much practical use.

Derek C. Bok, *A Flawed System of Law Practice and Training*, 33 J. LEGAL EDUC. 570, 580 (1983).

from central control to make individual tragic choices.¹⁹

Compared to these problems with a socially codified definition of futility, a clinical sense of futility that is employed by prudent and accountable professionals preserves individualized treatment decisions in relation to particular clinical circumstances, evolving medical knowledge, and a social need to not explicitly devalue the lives of profoundly ill people. In addition to arguments for the impracticality of futility codes, a discretionary and prudential clinical authority to use medical futility is likely to be a social policy that on balance protects individuals from the arbitrary exercise of power.²⁰

It is arbitrary and dishonest to assert that health care providers (under threat of losing their entire access to Medicare funds) must provide a respirator to anencephalic Baby K *because of respect for life and autonomy in a society* where living wills are not accepted as a substitute for health insurance for routine, effective health care. It is an elite, academic sophistry (not practical, serious, civic, moral reflection) to equate years of respirator support for an anencephalic baby, cryogenic suspension of a person with untreatable pancreas cancer, or years of intensive care for an eighty-seven year old permanently unconscious, respirator dependent woman with the decisions about ordinary access to penicillin, vaccinations, or appendectomies, which are routinely used and widely recognized as beneficial.

The failure to ground the right of access to common health care resources, based on a shared definition of the normative purposes of the health care system (defined by society or the medical profession), reduces all access disputes to precisely the kind of squeaky wheel or power ethics that Morreim properly deplores.²¹ Futility is only about whose power trumps, if one has presumed that societal codes or prudential professional opinion cannot provide a serviceable account of the ends of ordinary medical care that can be used to support ordinary access to the health care commons. The conclusion that the entitlement to health care simply boils down to power, rather than a common sense of the purpose and good of health care, is socially disintegrative and enhances the likelihood that any disempowered (read "medically indigent") per-

¹⁹ GUIDO CALABRESI & PHILIP BOBBIT, TRAGIC CHOICES 49, 58, 78, 145 (1978); Steven H. Miles, *Medical Futility*, 20 L., MED., & HEALTH CARE 310 (1993).

²⁰ See Howard Brody, *The Physician's Role in Determining Futility*, 42 J. AM. GERIATRIC SOC'Y 875, 875-78 (1993).

²¹ See E. Haavi Morreim, *Profoundly Diminished Life: The Casualties of Coercion*, HASTINGS CENTER REP., Jan.-Feb. 1994, at 33.

son will be denied ordinary effective health care. This result loads the media gun, which allows a mother's claim for a respirator for an anencephalic baby to hijack Medicaid resources in a state which cannot mobilize the civic moral consensus about the good and purpose of health care to enable the state to vaccinate its children.

III. LOCATING FUTILITY

A serviceable construction of medical futility must be grounded in the definition of "standard of care."²² As such, it will be a somewhat fuzzy term, one in which the clinician is accountable to evolving medical knowledge, compelling individual circumstances, larger professional standards, and prudential decisionmaking. Professional societies²³ must assume a leading role in proposing this standard of care, which in turn must face and survive public scrutiny and debate. To develop discretionary rules for handling futility disputes, such disputes must take place in the form of civic debate between the health profession and society, rather than in individual clinical disputes at the bedside. Society, courts, and health care plans must develop due process rules for handling futility disputes. Such rules should provide for full disclosure of the nature of futility decisions, processes for appeals, and options for going outside the health care system for self-payment.

IV. FUTILITY AND THE CRISIS OF PROFESSIONALISM

The debate about futility and medical professionalism echoes concerns about legal professionalism that are raised by Derek Bok²⁴ and Sol Linowitz.²⁵ The physician's fiduciary responsibility to patients (like that of lawyers to clients) must at some level acknowledge that advocacy for a patient's rights implies refraining from demands for process rights or entitlements that are fundamentally incompatible with comparable opportunities for others. In this tension, the professional who serves a fiduciary trust is also a conservator of the social contract which is the wellspring of the client's rights and entitlements. Neither lawyers nor physicians can expect government to so explicitly codify professional duties or so precisely delimit rights or entitlements in a way that is as nuanced,

²² A legal framework for addressing the liability issues in this authority is possible. See Frank H. Marsh & Allen Staver, *Physician Authority for Unilateral DNR Orders*, 12 J. LEGAL MED. 115 (1991).

²³ See *supra* note 4 for a list of some of these societies.

²⁴ See Bok, *supra* note 18.

²⁵ See SOL M. LINOWITZ, *BETRAYED PROFESSION: LAWYERING AT THE END OF THE TWENTIETH CENTURY* (1994).

as protective of the broadest forms of advocacy, and as capable of prudent exception and humane evolution as the institutions of prudential, discretionary, and client-centered professionalism. Medical futility, however narrow its scope, is an element of professional responsibility.