

Mental Hygiene Law Article 81:  
Guardianship and Personal Needs Issues

Wayne Olinzock, Esq.  
*Principal Attorney*  
*Mental Hygiene Legal Service*  
*Third Judicial Department*

**Wayne E. Olinzock - Principal Attorney - MHLS - Albany Regional Office**

After graduating St Francis College Wayne Olinzock was employed as a Public Health Advisor with the New York City Department of Health. Thereafter, he earned his Bachelor of Science in Nursing from the Hunter-Bellevue School of Nursing and worked as a Registered Nurse in various hospitals throughout NYC with experience in intensive care, emergency room, medical surgical and psychiatric nursing. He graduated from St. John's University School of Law in 1988 and worked in private practice as in-house counsel for AIG. He has worked as a prosecutor for the New York State Bureau of Professional Medical Conduct and has been employed at MHLS for over twenty years representing the mentally disabled and forensic patients in a variety of matters including involuntary retention, involuntary medication and assisted outpatient treatment proceedings. He has been assigned as counsel and court evaluator in hundreds of guardianship proceedings pursuant to MHL art 81 and SCPA 17-A, and also provides representation to the developmentally disabled in a variety of matters including the establishment of trusts, appearing in surrogate decision making hearings, and reviewing applications concerning the withholding or withdrawing of life sustaining treatment pursuant to Surrogate's Court Procedure Act § 1750 b. He has conducted presentations to the New York State Bar Association, hospitals, health care professionals and associations concerning various aspects of guardianship, the mental hygiene law, health care proxies, and the implementation of SCPA 1750-b.

## GUARDIANSHIP AND PERSONAL NEEDS ISSUES

### BACKGROUND

With the passage of the Family Health Care Decisions Act in 2010 (Public Health Law Article 29-CC, hereinafter the FHCDA), New York codified the standards for a surrogate to make medical decisions for an incapacitated person including the withholding or withdrawing of life sustaining treatment.

At common law, the right to refuse treatment was considered personal to the patient and could not be exercised by a third party unless there was clear and convincing evidence that the patient made a prior competent choice to decline the treatment (*Matter of Storar*, 52 NY2d 363 [1981]; *Matter Westchester County Med. Ctr. [O'Connor]*, 72 NY2d 517 [1988]).

In 1987, the Legislature delineated limited circumstances in which a surrogate could consent to a do not resuscitate (DNR) order for an incapacitated individual (Public Health Law Art. 29-B). In 1990, Public Health Law Article 29-C codified the common law right of a competent adult to determine the course of his or her own medical treatment by appointing a health care agent to make decisions in the event of his or her subsequent incapacitation.

The limitations of an Article 81 guardian to make end of life decisions prior to the FHCDA were made clear by the Court in *Matter of Kyle*, 165 Misc.2d 175 (Sup. Ct. Suffolk Cty., 1995). Here the Article 81 guardian sought to withhold the insertion of a feeding tube for an individual who, as the result of a stroke, could no longer swallow and ingest food. The Court held that the right to decline treatment is a personal one

which cannot be exercised by a third party if the patient is unable to do so unless a health care proxy or DNR order is in place, or there is otherwise clear and convincing evidence of the patient's wishes regarding such treatment while he or she was competent.

In 2003, the Legislature enacted a statute in derogation of the common law rule to permit SCPA Article 17-A guardians of mentally retarded persons to withhold or withdraw life sustaining treatment in narrow circumstances. SCPA 1750-b was enacted to address the perceived harshness of the decision in *Matter of Storar*, 52 NY2d 363 *supra*, because some mentally retarded persons, due to their cognitive limitations, were never able to formulate an opinion on the issue of life-sustaining treatment.

#### FAMILY HEALTH CARE DECISIONS ACT

In 2010, the FHCDCA codified the standards allowing surrogates to make medical decisions for incapacitated individuals including the right to withhold or withdraw life-sustaining treatment.

" 'Life-sustaining treatment' means any medical treatment or procedure without which the patient will die within a relatively short time, as determined by an attending physician to a reasonable degree of medical certainty. For the purpose of this article, cardiopulmonary resuscitation is presumed to be life sustaining treatment without the necessity of a determination by an attending physician." (PHL art 29-CC §2994-a [19]).

The FHCDCA pertains to incapacitated individuals in a general hospital, residential health care facility, *i.e.*, a nursing home or facility providing health related services, or hospice care provided in a facility or at home (PHL §2994-a [17-a] [18] [28], §2994-b).

Incapacity is determined by the attending physician to a reasonable degree of medical certainty (PHL §2994-c [2]) with a concurring opinion to be made by a health or

social services practitioner (PHL §2994-c [3] [b] [i] [ii] [iii]).<sup>1</sup> Determinations of incapacity for the mentally ill and developmentally disabled have their own specific requirements (PHL §2994-c [3] [c] [i] [ii]).

For treatment decisions for incapacitated individuals receiving services due to a developmental disability, the statute refers the health care provider and surrogate to SCPA 1750-b or appropriate regulations promulgated by the Office for People With Developmental Disabilities.<sup>2</sup> For those incapacitated and institutionalized due to mental illness, decision making is governed by the regulations promulgated by the Office of Mental Health (PHL §2994-b [3] [a] [b] [c]).

Prior competent choices obviate the need for a surrogate to intervene (PHL §2994-d [3] [ii]).

Notwithstanding a determination of incapacity, if the patient objects to said determination, to the choice of surrogate, or to a decision made by a surrogate, the objection prevails unless "(a) a court of competent jurisdiction has determined that the patient lacks decision-making capacity or the patient is or has been adjudged incompetent for all purposes and, in the case of a patient's objection to treatment, makes any other finding required by law to authorize the treatment, or (b) another legal basis exists for overriding the patient's decision." (PHL §2994-c [6]).

Surrogates who may act, in order of priority, are:

---

<sup>1</sup> Health or social services practitioner is defined in PHL §2994-a (17) as a, "registered professional nurse, nurse practitioner, physician, physician assistant, psychologist or licensed clinical social worker, licensed or certified pursuant to the education law acting within his or her scope of practice."

<sup>2</sup> SCPA §1750-b mirrors the requirements of the FHCDA with some exceptions and pertains to individuals with a diagnosis of developmental disability which includes mental retardation.

- a guardian authorized to decide about health care pursuant to article 81
- the spouse, if not legally separated, or the domestic partner
- a son or daughter eighteen years of age or older
- a parent
- a brother or sister eighteen years of age or older
- a close friend (PHL §2994-d).

The surrogate shall make health care decisions in accordance with the patient's wishes, including the patient's religious and moral beliefs; or in accordance with his or her best interests if they are not reasonably known and cannot with due diligence be ascertained (PHL §2994-d [4]).

A surrogate can decide to withdraw or withhold life-sustaining treatment for an incapacitated person when:

the treatment would be an extraordinary burden and,

the attending physician with the concurrence of an independent physician determines to a reasonable degree of medical certainty and in accord with accepted medical standards that:

- the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided or,
- the patient is permanently unconscious or,
- treatment would involve such pain and suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition (PHL §2994-d [5] [a] [i] [ii]).

If the patient is in a residential care facility and the physicians have decided to withdraw treatment utilizing the pain and suffering standard, the ethics review committee of that facility, including one physician not directly responsible for the

patient's care, or a court of competent jurisdiction, must concur. However, this requirement shall not apply to cardiopulmonary resuscitation (PHL §2994-d [5] [b]).

In 2010, Article 81 was amended. Pursuant to MHL §81.22 (a) (8) decisions for incapacitated persons by a personal needs guardian shall be made in accordance with the standards set forth in the FHCDA.<sup>3</sup>

## CASE LAW

### A. Legislative Intent

In *Matter of Restaino (AG)*, 37 Misc.3d 586 (Sup. Ct. Nassau Cty., 2012) the Court held that a residential facility/hospital should not petition the Court for the appointment of a special guardian for the sole purpose of seeking Medicaid benefits when the patient is clearly incapacitated and needs a guardian of the person. It found that the legislative intent of the FHCDA was to fill a gap and provide a procedure to facilitate responsible decision making by surrogates on behalf of patients without capacity and was never intended as a substitute for an Article 81 personal needs guardian.

The Court reasoned that: (1) under the FHCDA, there is a presumption that an adult has decision making capacity unless an Article 81 guardian has been authorized to make health care decisions or there has otherwise been an adjudication of incapacity, thus allowing the patient's objection to prevail and; (2) the potential powers of a guardian of the person are more extensive than the authority of a surrogate under

---

<sup>3</sup> MHL § 81.22 (a) (8) was amended so that the personal needs guardian has the right to, "(i) for decisions in hospitals as defined by subdivision eighteen of section twenty-nine hundred ninety-four-a of the public health law, act as the patient's surrogate pursuant to and subject to article 29-CC of the public health law, and (ii) in all other circumstances, to consent to or refuse generally accepted routine or major medical or dental treatment, subject to the decision-making standard in subdivision four of section twenty-nine hundred ninety-four-d of the public health law."

the FHCDA. Therefore, even though the petitioner nursing home did not seek the appointment of a guardian of the person, the Court, after conducting an evidentiary hearing, appointed the patient's son as personal needs guardian. and the nursing home special guardian of the property.

#### B. Honoring the Preferences of the Terminally Ill Person

In *Matter of Northern Manhattan Nursing Home (A.M.)*, 32 Misc.3d 754 (Sup. Ct. New York Cty., 2011), the Article 81 personal and property needs guardian (the Vera Institute of Justice, Guardianship Project) appointed in 2008, brought an emergency order to show cause seeking to withhold the insertion of a percutaneous endoscopic gastrostomy (PEG) feeding tube, diagnostic testing and treatment for a 92 year-old man with dementia and metastatic cancer. The Court found that there was sufficient documentary medical evidence and testimony that he had a terminal illness, that further treatment would be medically futile, that he would die within six months with or without treatment, and that further treatment would cause pain and suffering. Although the guardian was unable to ascertain his preferences and wishes in the past, the patient, a Catholic, was not interested in speaking with a priest when lucid, and had refused to permit even such minor medical procedures as the taking of blood samples. The Court, therefore, granted the application.

In *Borenstein v. Simonson* 8 Misc. 3d 481 (Sup. Ct. Queens Cty., 2005), a case decided prior to the enactment of the FHCDA, an 86 year old woman with advanced dementia had filled out a health care proxy some years prior but gave no instructions as to artificial nutrition and hydration. She merely stated in the document that " 'If there is any hope of recovery, I want my agent to ask for life sustaining treatment.' " (at 483).

The mother/principal lost the ability to eat and was being fed by nasogastric tube, which is only a temporary measure. When her daughter/agent was asked to consent to a PEG tube she refused stating her mother had almost no quality of life. The principal's sister brought suit and it was determined that the principal had never specifically expressed her wishes about artificial nutrition and hydration but had expressed an " 'evolved commitment to traditional or religious Judaism....' " (at 486).

Judge Ritholtz, noted in his decision that PHL §2882 (2) does not allow a health care agent to make decisions about artificial nutrition and hydration if the principal's wishes are not known or cannot be reasonably ascertained. He went on to discuss the split opinion as to whether artificial nutrition and hydration is medical treatment or supportive humanistic care. He noted that those who distinguish nutrition and hydration from other forms of medical treatment point out that withdrawal of such is frequently an independent cause of death by gradual starvation and dehydration and not from the underlying disease.

Citing authorities in Jewish law, he noted that artificial nutrition and hydration is viewed as supportive care, no different from washing and grooming and turning a patient. He does, however, point out that in certain circumstances, as with a terminal patient where death is imminent, such intervention may not be warranted.

Judge Ritholtz concluded that the principal is entitled, in her own words, " 'to life sustaining treatment' " and that "we must never forget that" (quoting a Dr. Fred Rosner) " 'when the quality of life replaces the sanctity of life, society has done itself irreparable harm.' " (at 501).

In *Matter of Zornow*, 31 Misc. 3d 450, (Sup. Ct., Monroe Cty. 2010), (clarified at

34 Misc.3d 1208[A]), a 93 year old devout Catholic female, suffering from advanced Alzheimer's Disease and who had not appointed a health care agent, was the subject of medical orders which denied her CPR, artificial nutrition and hydration, and hospitalization for future medical conditions. Under the FHCDA, the guardian was obligated to make such decisions in accordance with the patient's religious beliefs. The Court conducted an evidentiary hearing and found clear and convincing evidence that the patient wanted artificial nutrition and hydration and that the applicable principles to be applied to her end of life decision were those of her Roman Catholic beliefs. The Court then reviewed those principles to determine under what conditions artificial nutrition and hydration could be terminated.

Here, Justice Polito noted that the FHCDA reflects a major departure from a prior presumption of life to a presumption of termination. He notes that a health care agent appointed by a principal cannot withhold artificial and hydration absent an indication to the contrary (PHL §2982 [2]), while a surrogate designated by the FHCDA can terminate life despite the principal never having indicated a desire for such termination. Thus, he concluded, the "quality of life ethic" has replaced the "sanctity of life" ethic.

The Court discussed in great detail Catholic doctrine and concluded that under the "sanctity of life" doctrine of the Church, in nearly every instance, hydration and nutrition, even when administered artificially, are considered to be ordinary rather than extraordinary measures, and that hydration and nutrition must be administered except under certain narrow exceptions. The Court also held that guardians should consult with a priest or someone well trained in Catholic moral theology.

In his later opinion clarifying his initial opinion, Justice Polito states that under

either the FHCDA, which dictates one's religious beliefs be followed, or *Matter of O'Connor*, 72 NY2d 517, *supra*, the dying person is under no legal obligation to provide clear and convincing evidence that he or she would want ordinary treatment such as artificial nutrition and hydration, only that he or she would not.

### C. Retroactivity

In *Matter of Erie County Med. Ctr. Corp. (Doe)*, 33 Misc.3d 1208(A) (Sup. Ct. Erie County 2011) the petitioner, an Article 81 guardian/skilled nursing facility where respondent resided, was appointed prior to the enactment of the FHCDA. Petitioner moved pursuant to MHL Article 81 and the FHCDA to retroactively expand its authority to consent to the withholding and withdrawing of life-sustaining treatment for respondent diagnosed with advanced dementia, failure to thrive, normal pressure hydrocephalus and anorexia. Based on the condition of the respondent, her consent through her counsel and prior competent choices, the expansion of the guardian's powers to provide comfort measures only was granted.

The Court found persuasive support for retroactive application of the FHCDA in *Matter of Zornow*, 31 Misc. 3d 450, *supra*, the repeal of MHL § 81.29 (e) which provided that it was not to be construed as either prohibiting or authorizing a court to grant any person the power to give consent for the withholding or withdrawal of life-sustaining treatment, and the statement of the NYS Bar Association that it anticipated the FHCDA would be judicially applied to Article 81 guardians appointed prior to June 1, 2010, the effective date of the FHCDA.

#### D. Guardianship on Consent

In *Matter of Buffalino (James D.)*, 39 Misc.3d 634 (Sup. Ct. Suffolk Cty., 2013), the Court dealt with a motion for discharge by James D. who had originally consented to a guardian. The successor guardian then moved for an order determining Mr. D to be incapacitated, and to expand the powers of the guardianship. Mr. D then cross-moved to discharge the successor guardian. The initial guardianship was granted on consent without a finding of incapacity as permitted by MHL §§ 81.02 and 81.15.

In its discussion the Court indicated that, in determining a person's capacity to agree to a guardianship it, "will generally consider the individual's ability to meaningfully interact and converse with the Court, his or her understanding of the nature of the proceeding, and his or her comprehension of the powers being relinquished." (at 636). The inquiry, it found, is not the equivalent of the in-depth examination which occurs at a full hearing to determine incapacity.

Here the Court noted that, "[a] consent guardianship is created on the basis of the individual's agreement thereto and it does not morph into a non-consent guardianship with its inherent finding of incapacity because an emergency occurs and an expansion of powers becomes necessary." (at 637). Therefore, where the original guardianship was made upon consent, the guardian was prohibited from seeking to expand his powers pursuant to MHL § 81.36 over the objection of his ward. The Court treated the application as a new guardianship petition and, after an evidentiary hearing, found there was not clear and convincing evidence for a guardian.

## ETHICAL CONSIDERATIONS

The FHODA requires that the surrogate consider the individual's wishes, including his/her religious and moral beliefs when evaluating whether further treatment should be provided or is an extraordinary burden. Extraordinary burden is not defined in the statute. In these murky waters the medical provider and surrogate must weigh the efficacy of a proposed treatment against the physical and psychological cost to the patient. When the treatment being considered is of questionable value, is not curative, or will only prolong the inevitable, the issue of futility arises. Unfortunately, medical futility can have several meanings.

A review of the medical literature provides some insight. One group of authors defines futility as "an effort to achieve a result that is possible but that reasoning or experience suggests is highly improbable and cannot be systematically produced." The authors go on to state that futility may refer: (1) quantitative futility - an improbability or unlikelihood of an event happening, an expression that is quasi-numeric (in the last 100 cases treatment has been useless) or (2) qualitative futility - the quality of the event that treatment would produce (treatment that merely preserves permanent unconsciousness or fails to end total dependence on intensive medical care). (See Schneiderman et. al. *Medical Futility: Its Meaning and Ethical Implications* [attached]).

Another author talks of post-hoc futility (treatment tried and failed) and predictive futility (predicting treatment that will be futile and should not be tried). He goes on to break down predictive futility into four types:

- conceptual futility - based on a concept or definition (e.g., brain death)
- probabilistic futility - based on a low chance of success (e.g., CPR for the elderly patient with cardiac problems)

- medical impasse - a treatment would be physiologically impossible (CPR for an AIDS patient with pneumonia and continued respiratory distress)
- doctor - patient goal disagreement - (e.g., patient in Persistent Vegetative State and physician's goal is for health improvement and husband's goal is for prolongation of life) (Walker, *Ethical Issues in End of Life Care* [attached]).

The withholding or withdrawing of life-sustaining treatment is often fraught with emotion for the families and loved ones who are involved. Analyzing a given situation with these concepts in mind can assist the clinicians and the surrogate in weighing the benefits and costs to the patient against the expected outcome.

## MEDICINE AND PUBLIC ISSUES

**Medical Futility: Its Meaning and Ethical Implications**

Lawrence J. Schneiderman, MD; Nancy S. Jecker, PhD; and Albert R. Jonsen, PhD

The notion of medical futility has quantitative and qualitative roots that offer a practical approach to its definition and application. Applying these traditions to contemporary medical practice, we propose that when physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of published empiric data) that in the last 100 cases a medical treatment has been useless, they should regard that treatment as futile. If a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive medical care, the treatment should be considered futile. Unlike decision analysis, which defines the expected gain from a treatment by the joint product of probability of success and utility of outcome, our definition of futility treats probability and utility as independent thresholds. Futility should be distinguished from such concepts as theoretical impossibility, such expressions as "uncommon" or "rare," and emotional terms like "hopelessness." In judging futility, physicians must distinguish between an effect, which is limited to some part of the patient's body, and a benefit, which appreciably improves the person as a whole. Treatment that fails to provide the latter, whether or not it achieves the former, is "futile." Although exceptions and cautions should be borne in mind, we submit that physicians can judge a treatment to be futile and are entitled to withhold a procedure on this basis. In these cases, physicians should act in concert with other health care professionals, but need not obtain consent from patients or family members.

*Annals of Internal Medicine.* 1990;112:949-954.

From the School of Medicine, University of California, San Diego, La Jolla, California; and the University of Washington School of Medicine, Seattle, Washington. For current author addresses, see end of text.

A 62-year-old man with irreversible respiratory disease is in the intensive care unit. He is severely obtunded. During 3 weeks in the unit, repeated efforts to wean him from ventilatory support have been unsuccessful. There is general agreement among his physicians that he could not survive outside of an intensive care setting. They debate whether therapy should include cardiopulmonary resuscitation if the patient has a cardiac arrest or antibiotics if he develops infection. The patient gave no previous indication of his wishes nor executed an advance directive. Some physicians argue that a "do not resuscitate" order may be written without consulting the family, because resuscitation would be futile. Other physicians object, pointing out that resuscitation cannot be withheld on grounds of medical futility, because the patient could survive indefinitely in the intensive care unit. They agree to consult the family on this matter. At first there is considerable disagreement

within the family until a son asks whether there is any hope at all that his father might recover. The physicians look at each other. There is always hope. This unites the family. They insist that if the situation is not hopeless, the physicians should continue all measures including resuscitation.

How should these physicians deal with this family's demands? The answer depends on both how the physicians define futility and the weight they give it when patients or surrogates strongly express treatment preferences. Are these issues perhaps too complex or ambiguous to resolve (1, 2)? We submit that they are not, and we offer both a theoretical and practical approach to the concept of futility, an approach that we believe serves in this case and more generally in similar cases by restoring a common sense notion of medical duty. We recognize that if futility is held to be nothing more than a vague notion of physician discretion, it is subject to abuse; therefore, we propose specific standards by which this idea can be appropriately invoked. In our view, judgments of futility emerge from either quantitative or qualitative evaluations of clinical situations. Such evaluations determine whether physicians are obligated to offer an intervention. If an intervention is judged to be futile, the duty to present the intervention as an option to the patient or the patient's family is mitigated or eliminated. We recognize—indeed invite—examination and challenge of our proposal.

**The Glare of Autonomy**

Less than a few decades ago, the practice of medicine was characterized by a paternalism exemplified in the expression, "doctor's orders." Physicians determined by themselves or in consultation with colleagues the usefulness of courses of treatment. The art of medicine was considered to include selectively withholding as well as disclosing information in order to maintain control over therapy. The dramatic shift toward patient self-determination that has taken place in recent decades almost certainly received much of its momentum from society's backlash to this paternalism. In addition, philosophical and political concerns about the rights of individuals and respect for persons elevated the principle of autonomy to a position in ethics that it had not previously held. Today, ethics and the law give primacy to patient autonomy, defined as the right to be a fully informed participant in all aspects of medical decision making and the right to refuse unwanted, even recommended and life-saving, medical care. So powerful has this notion of autonomy become that its glare often blinds physicians (and ethicists) to the validity of earlier maxims that had long defined the range of physicians' moral obligations toward patients. Among these was the maxim, respected in ethics and law, that futile treat-

ments are not obligatory. No ethical principle or law has ever required physicians to offer or accede to demands for treatments that are futile (3, 4). Even the so-called Baby Doe regulations, notorious for their advocacy of aggressive medical intervention, permit physicians to withhold treatment that is "futile in terms of the survival of the infant" or "virtually futile" (5). Even when this maxim is accepted in theory, however, physicians frequently practice as though every available medical measure, including absurd and overzealous interventions, must be used to prolong life unless patients give definitive directions to the contrary (6, 7). Some physicians allow patients (or surrogates) to decide when a treatment is futile, thereby overriding medical judgment and potentially allowing the patient (or surrogate) to demand treatment that offers no benefit (8).

#### Comparison of Effect and Benefit

In the early nineteenth century, all medications were, by definition, effective: They inevitably brought about the effect that their names described. Emetics could be counted on to cause vomiting; purgatives to cause laxation; sudorifics, sweating; and so on (9). These effects, given the medical theories of the times, were presumed always to be beneficial. Failure to heal was a defect of nature, not of the physician or the treatment. However, one advance of modern medicine, particularly with the introduction of controlled clinical trials, was to clarify by empiric methods the important distinction between effect and benefit. In examining the notion of futility, physicians sometimes fail to keep this distinction in mind.

For example, a recent discussion of futility includes the following: "[Physicians] may acknowledge that therapy is effective, in a limited sense, but believe that the goals that can be achieved are not desirable, as when considering prolonged nutritional support for patients in a persistent vegetative state. Physicians should acknowledge that, in such situations, potentially achievable goals exist. Therapy is not, strictly speaking, futile" (2). On the contrary, we believe that the goal of medical treatment is not merely to cause an effect on some portion of the patient's anatomy, physiology, or chemistry, but to benefit the patient as a whole. No physician would feel obligated to yield to a patient's demand to treat pneumonia with insulin. The physician would rightly argue that (in the absence of insulin-requiring diabetes) such treatment is inappropriate; insulin might have a physiologic effect on the patient's blood sugar, but would offer no benefit to the patient with respect to the pneumonia. Similarly, nutritional support could effectively preserve a host of organ systems in a patient in persistent vegetative state, but fail to restore a conscious and sapient life. Is such nutritional treatment futile or not? We argue that it is futile for the simple reason that the ultimate goal of any treatment should be improvement of the patient's prognosis, comfort, well-being, or general state of health. A treatment that fails to provide such a benefit—even though it produces a measurable effect—should be considered futile.

#### Approaching a Definition

The word futility comes from the Latin word meaning leaky (*futillis*). According to the *Oxford English Dictionary*, a futile action is "leaky, hence untrustworthy, vain, failing of the desired end through intrinsic defect." In Greek mythology, the daughters of Danaus were condemned in Hades to draw water in leaky sieves. Needless to say, their labors went for naught. The story conveys in all its fullness the meaning of the term: A futile action is one that cannot achieve the goals of the action, no matter how often repeated. The likelihood of failure may be predictable because it is inherent in the nature of the action proposed, and it may become immediately obvious or may become apparent only after many failed attempts.

This concept should be distinguished from etymologic neighbors. Futility should not be used to refer to an act that is, in fact, impossible to do. Attempting to walk to the moon or restore cardiac function in an exsanguinated patient would not be futile acts; they would be physically and logically impossible. Nor should futility be confused with acts that are so complex that, although theoretically possible, they are implausible. The production of a human infant entirely outside the womb, from in-vitro combination of sperm and egg to physiologic viability, may be theoretically possible but, with current technology, is implausible.

Further, futile, because the term is not merely descriptive, but also operational, denoting an action that will fail and that ought not be attempted, implies something more than simply rare, uncommon, or unusual. Some processes that are quite well understood and quite probable may occur only occasionally, perhaps because of their complexity and the need for many circumstances to concur at the same time. For example, successful restoration to health of a drug addict with bacterial endocarditis might require a combination of medical, psychological, social, and educational efforts. These interventions could work but, due to various factors (including limited societal resources), they rarely work. However, they are not futile.

Futility should also be distinguished from hopelessness. Futility refers to the objective quality of an action; hopelessness describes a subjective attitude. Hope and hopelessness bear more relation to desire, faith, denial, and other psychological responses than to the objective possibility or probability that the actions being contemplated will be successful. Indeed, as the chance for success diminishes, hope may increase and replace reasonable expectation. Something plausible is hardly ever hopeless, because hope is what human beings summon up to seek a miracle against overwhelming odds. It is possible then to say in the same breath, "I know this is futile, but I have hope." Such a statement expresses two facts, one about the objective properties of the situation, the other about the speaker's psychological state.

Futility refers to an expectation of success that is either predictably or empirically so unlikely that its exact probability is often incalculable. Without specific data, one might predict futility from closely analogous experience. (For example, one might avoid a trial of a

particular chemotherapy for one type of cancer based on failures seen when used for treating similar forms of cancer.) Or one may have accumulated empiric experience insufficient to state precisely the likelihood of success, but sufficient to doubt the likelihood of success. (For example, physicians have had only a few years of experience with a currently popular medication to cure baldness, but sufficient experience to be dubious of its long-term success.)

Reports of one or two "miraculous" successes do not counter the notion of futility, if these successes were achieved against a background of hundreds or thousands of failures. Such rare exceptions are causally inexplicable, because any clinical situation contains a multitude of factors—in addition to treatment—that might affect outcome. As Wanzer and colleagues (10) stated, "The rare report of a patient with a similar condition who survived is not an overriding reason to continue aggressive treatment."

#### Quantitative and Qualitative Aspects

The futility of a particular treatment may be evident in either quantitative or qualitative terms. That is, futility may refer to an improbability or unlikelihood of an event happening, an expression that is quasi-numeric, or to the quality of the event that treatment would produce. Thus, determining futility resembles using decision analysis—with one important distinction. In decision analysis, the decision to use a procedure is based on the joint product of the probability of success and the quality (utility) of the outcome (11). Thus, very low probability might be balanced by very high utility. In our proposal of futility, however, we treat the quantitative and qualitative aspects as independent thresholds, as minimal cutoff levels, either of which frees the physician from the obligation to offer a medical treatment.

This independence of futility determinants can be traced back to medical antiquity (12, 13). The perception of futility derived from the Hippocratic corpus might be considered, in modern terms, to be quantitative or probabilistic. A book titled "The Art" (14) enjoins physicians to acknowledge when efforts will probably fail: "Whenever therefore a man suffers from an ill which is too strong for the means at the disposal of medicine, he surely must not even expect that it can be overcome by medicine." The writer further admonishes the physician that to attempt futile treatment is to display an ignorance which is "allied to madness."

Plato's *Republic* (15), on the other hand, has a qualitative notion of futility, one that emphasizes the inappropriateness of efforts that result in patients surviving, but leading literally useless lives. According to Plato, the kind of medicine "which pampers the disease" was not used by the Asclepian physicians:

Asclepius . . . taught medicine for those who were healthy in their nature but were suffering from a specific disease; he rid them of it . . . then ordered them to live as usual . . . For those however, whose bodies were always in a state of inner sickness he did not attempt to prescribe a regimen . . . to make their life a prolonged misery . . . Medicine

was not intended for them and they should not be treated even if they were richer than Midas.

Thus, both the quantitative and qualitative aspects of futility are recognized in the most ancient traditions. Hippocrates rejects efforts that are quantitatively or probabilistically unlikely to achieve a cure; Plato objects to a cure consummating (qualitatively) in a life that "isn't worth living." Both quantitative and qualitative aspects relate to a single underlying notion: The result is not commensurate to the effort. The effort is, on the part of the agent, a repeated expenditure of energy that is consistently nonproductive or, if productive, its outcome is far inferior to that intended.

#### Defining Futility

We propose that, on the basis of these considerations, the noun "futility" and the adjective "futile" be used to describe any effort to achieve a result that is possible but that reasoning or experience suggests is highly improbable and that cannot be systematically produced. The phrase, "highly improbable," implies that a statistical statement about probability might be applicable. In the strict sense, such a statement cannot be made, as proper conditions for determining probability (that is, prospective comparisons of precisely controlled treatment and nontreatment on identically matched subjects) will never be present. We introduce the concept of "systematic" to point out that if a rare "success" is not explicable or cannot be predictably repeated, its causality is dubious, because it is uncertain whether treatment, some extraneous influence, or random variation caused the result.

#### Quantitative Aspects

In keeping with the quantitative approach to futility, we propose that when physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of reported empiric data) that in the last 100 cases, a medical treatment has been useless, they should regard that treatment as futile. Technically, we cannot say that observing no successes in 100 trials means that the treatment never works. However, such an observation serves as a point estimate of the probability of treatment success. Although we cannot say with certainty that the point estimate is correct, statistical methods can be used to estimate a range of values that include the true success rate with a specified probability. For example, if there have been no successes in 100 consecutive cases, the clinician can be 95% confident that no more than 3 successes would occur in each 100 comparable trials (3 successes per 100 trials is the upper limit of the 95% CI). This confidence range would narrow as the number of observations increased. If no successes were seen in 200 cases, the upper limit of the 95% CI would be 1.5 successes per 100 cases and, for no successes in 1000 observations, the upper limit would be approximately 0.3 successes per 100 cases. In practical terms, because data from controlled clinical trials can only rarely be called on and applied to a specific case, practitioners usually use their

extended experience as the source of their conclusions. Here, speciality practice contributes an essential element; for example, an intensive care pulmonary specialist who sees several hundred patients who have similar disease conditions and receive similar therapy can often group together "futility characteristics" better than a generalist who does not see cases in so focused a manner.

Without systematic knowledge of the various factors that cause a therapy to have less than a 1% chance of success—knowledge that would allow the physician to address these factors—we regard it as unreasonable to require that the physicians offer such therapy. To do so forces the physician to offer any therapy that may have seemed to work or that may conceivably work. In effect, it obligates the physician to offer a placebo. Only when empirically observed (though not understood) outcomes rise to a level higher than that expected by any placebo effect (16), can a specific therapy be considered to be "possibly helpful" in rare or occasional cases and its appropriateness evaluated according to rules of decision analysis. In the clinical setting, such judgments also would be influenced, of course, by considering such tradeoffs as how cheap and simple the intervention is and how serious or potentially fatal the disease (*see* Exceptions and Cautions).

Although our proposed selection of proportions of success is admittedly arbitrary, it seems to comport reasonably well with ideas actually held by physicians. For example, Murphy and colleagues (17) invoked the notion of futility in their series of patients when survival after cardiopulmonary resuscitation was no better than 2% (upper limit of 95% CI as calculated by authors), and Lantos and colleagues (18) when survival was no better than 7% (upper limit of 95% CI as calculated by authors).

Obviously, as medical data on specific situations are gathered under appropriate experimental conditions, empiric uncertainty can be replaced with empiric confidence (19). Admittedly, some disorders may be too rare to provide sufficient experience for a confident judgment of futility, even when efforts are made to pool data. We acknowledge this difficulty but adhere to our conservative standard to prevent arbitrary abuse of power. In judging futility, as in other matters, physicians should admit uncertainty rather than impose unsubstantiated claims of certainty. Therefore, our view of futility should be considered as encouraging rather than opposing well conducted clinical trials. Important examples of such work in progress include studies of survival after cardiopulmonary resuscitation (17-24) and use of prognostic measures in patients requiring intensive medical care (25, 26).

Already, data on burn patients (27) and on patients in persistent vegetative state with abnormal neuroophthalmic signs (28) are sufficient to help with decision making. The latter group of patients present a particular challenge to presently confused notions of futility, perhaps accounting in part for why an estimated 5000 to 10 000 patients in persistent vegetative state are now being maintained in medical institutions (29). The mythologic power of the coma patient who "wakes up" apparently overrides the rarity of documented confirma-

tion of such miraculous recoveries (which have resulted, moreover, in incapacitating mental impairment or total dependence) (28). This point bears on the frequently heard excuse for pushing ahead with futile therapies: "It is only by so doing that progress is made and the once futile becomes efficacious. Remember the futility of treating childhood leukemia or Hodgkin lymphoma." These statements hide a fallacy. It is not through repeated futility that progress is made, but through careful analysis of the elements of the "futile case," followed by well designed studies, that advances knowledge. We also point out that our proposal is intended for recognized illness in the acute clinical setting. It does not apply to preventive treatments, such as immunizations, estrogen prophylaxis for hip fractures, or penicillin prophylaxis for rheumatic heart disease and infectious endocarditis, all of which appear to have lower rates of efficacy because they are purposely administered to large groups of persons, many of whom will never be at risk for or identified with the particular diseases that their treatments are intended to prevent.

#### Qualitative Aspects

In keeping with the qualitative notion of futility we propose that any treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care should be regarded as nonbeneficial and, therefore, futile. We do not regard futility as "an elusive concept" (2). It is elusive only when effects on the patient are confused with benefits to the patient or when the term is stretched to include either considerations of 5-year survival in patients with cancer (not at all pertinent to the notion of futility) or the "symbolic" value to society of treating handicapped newborns or patients in persistent vegetative state (which rides roughshod over patient-centered decision making) (2).

Here is the crux of the matter. If futility is qualitative, why should the patient not always decide whether the quality achieved is satisfactory or not? Why should qualitatively "futile" results not be offered to the patient as an option? We believe a distinction is in order. Some qualitatively poor results should indeed be the patient's option, and the patient should know that they may be attainable. We believe, however, that other sorts of qualitatively poor results fall outside the range of the patient's autonomy and need not be offered as options. The clearest of these qualitatively poor results is continued biologic life without conscious autonomy. The patient has no right to be sustained in a state in which he or she has no purpose other than mere vegetative survival; the physician has no obligation to offer this option or services to achieve it. Other qualitatively poor results are conditions requiring constant monitoring, ventilatory support, and intensive care nursing (such as in the example at the beginning of our paper) or conditions associated with overwhelmingly suffering for a predictably brief time. Admittedly, these kinds of cases fall along a continuum, and there are well known examples of the most remarkable achievements of life goals despite the most burdensome handicaps. However, if survival requires the patient's entire preoccupa-

tion with intensive medical treatment, to the extent that he or she cannot achieve any other life goals (thus obviating the goal of medical care), the treatment is effective but not beneficial; it need not be offered to the patient, and the patient's family has no right to demand it.

Specifically excluded from our concept of futility is medical care for patients for whom such care offers the opportunity to achieve life goals, however limited. Thus, patients whose illnesses are severe enough to require frequent hospitalization, patients confined to nursing homes, or patients with severe physical or mental handicaps are not, in themselves, objects of futile treatments. Such patients (or their surrogates) have the right to receive or reject any medical treatment according to their own perceptions of benefits compared with burdens.

Some observers might object, as a matter of principle, to excluding patient input from assessments of qualitative futility. Others might be concerned that such exclusion invites abuse, neglect, and a retreat to the paternalistic "silent world" of the past in which doctors avoided communication with their patients (30). In response to the latter objection, we acknowledge that potential for abuse is present and share this concern. We would deplore the use of our proposal to excuse physicians from engaging patients in ongoing informed dialogue. Nonetheless, the alternative is also subject to abuse (for example, when legal threats made by patients and surrogates cow hospitals into providing excessive care). We reiterate that the distinction between medical benefit and effect justifies excluding patients from determination of qualitative futility. Physicians are required only to provide medical benefits to patients. Physicians are permitted, but not obligated, to offer other, non-medical benefits. For example, a physician is not obligated to keep a patient alive in an irreversible vegetative state, because doing so does not medically benefit the patient. However, as noted below, a physician may do so on compassionate grounds, when temporary continuance of biologic life achieves goals of the patient or family.

#### Exceptions and Cautions

We have attempted to provide a working definition of futility. We also have drawn attention to the ethical notion that futility is a professional judgment that takes precedence over patient autonomy and permits physicians to withhold or withdraw care deemed to be inappropriate without subjecting such a decision to patient approval. Thus, we regard our proposal as representing the ordinary duties of physicians, duties that are applicable where there is medical agreement that the described standards of futility are met. We recognize, however, that the physician's duty to serve the best interests of the patient may require that exceptions to our approaches be made under special circumstances.

An exception could well be made out of compassion for the patient with terminal metastatic cancer who requests resuscitation in the event of cardiac arrest to survive long enough to see a son or daughter who has

not yet arrived from afar to pay last respects. Such an exception could also be justified to facilitate coping and grieving by family members, a goal the patient might support (32-36). Although resuscitation may be clearly futile (that is, would keep the patient alive in the intensive care unit for only 1 or 2 more days), complying with the patient's wishes would be appropriate, provided such exceptions do not impose undue burdens on other patients, health care providers, and the institution, by directly threatening the health care of others. We hasten to add, however, that our notion of futility does not arise from considerations of scarce resources. Arguments for limiting treatments on grounds of resource allocation should proceed by an entirely different route and with great caution in our present open system of medical care, as there is no universally accepted value system for allocation (31) and no guarantee that any limits a physician imposes on his or her patients will be equitably shared by other physicians and patients in the same circumstances (37, 38).

Admittedly, in cases in which treatment has begun already, there may be an emotional bias to continue, rather than withdraw, futile measures (10). If greater attention is paid at the outset to indicating futile treatments, these situations would occur less frequently; however, the futility of a given treatment may not become clear until it has been implemented. We submit that physicians are entitled to cease futile measures in such cases, but should do so in a manner sensitive to the emotional investments and concerns of caretakers.

What if a hospitalized patient with advanced cancer demands a certain medication (for example, a particular vitamin), a treatment that the physician believes to be futile? Several aspects of this demand support its overriding the physician's invocation of futility. Certain death is expected and, although an objective goal such as saving the patient's life or even releasing the patient from the hospital might be unachievable, the subjective goal of patient well-being might be enhanced (a placebo-induced benefit). In this particular situation, the effort and resources invested to achieve this goal impose a negligible burden on the health care system and do not threaten the health care of others. Thus, although physicians are not obligated to offer a placebo, they occasionally do. For example, Imbus and Zawacki (27) allowed burn patients to opt for treatment even when survival was unprecedented. In this clinical situation, compassionate yielding imposes no undue burden, because survival with or without treatment is measured in days. In contrast, yielding to a surrogate's demand for unlimited life-support for a patient in persistent vegetative state may lead to decades of institutional care.

*Acknowledgments:* The authors thank two anonymous reviewers and Robert M. Kaplan, PhD, for their helpful comments.

*Requests for Reprints:* Lawrence J. Schneiderman, MD, University of California, San Diego, School of Medicine, Department of Community and Family Medicine, M-022, La Jolla, CA 92093.

*Current Author Addresses:* Dr. Schneiderman: University of California, San Diego, School of Medicine, Department of Community and Family Medicine, M-022, La Jolla, CA 92093.  
Dr. Jecker and Jonsen: School of Medicine, SB-20, University of Washington, Seattle, WA 98195.

## References

1. Younger SJ. Who defines futility? *JAMA*. 1988;260:2094-5.
2. Lantos JD, Singer PA, Walker RM, et al. The illusion of futility in clinical practice. *Am J Med*. 1989;87:81-4.
3. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions*. Washington DC: U.S. Government Printing Office; 1983:60-89.
4. Jonsen AR. What does life support support? *Pharos*. 1987;58(1):4-7.
5. *Child Abuse and Neglect Prevention and Treatment*. Washington, DC: U.S. Department of Health and Human Services, Office of Human Development Services; 1985: Federal Register 50:14887-8.
6. Blackhall LJ. Must we always use CPR? *N Engl J Med*. 1987;317:1281-5.
7. Tomlinson T, Brody H. Ethics and communication in do-not-resuscitate orders. *N Engl J Med*. 1988;318:43-6.
8. Le B. Life-sustaining treatment in patients with AIDS: challenge to traditional decision-making. In: Jucagst ET, Koenig BA, eds. *The Meaning of AIDS*. v 1. New York: Praeger; 1989:86-93.
9. Rosenzweig CE. The therapeutic revolution: medicine, meaning, and social change in nineteenth-century America. *Perspect Biol Med*. 1977;20:485-306.
10. Wanner SH, Adelman SJ, Cranford RE, et al. The physician's responsibility toward hopelessly ill patients. *N Engl J Med*. 1984;310:955-9.
11. Wehstein MC, Fhoberg HV. *Clinical Decision Analysis*. Philadelphia: W.B. Saunders; 1980.
12. Annasuden DW. The physician's obligation to prolong life: a medical duty without classical roots. *Hastings Cent Rep*. 1978;8:23-30.
13. Jonsen AR. *The Old Ethics and the New Medicine*. Cambridge: Harvard University Press; 1990.
14. Hippocratic corpus, the art. In: Reiser SJ, Dyck AJ, Curran WJ, eds. *Ethics in Medicine: Historical Perspectives and Contemporary Concerns*. Cambridge, Massachusetts: MIT Press; 1977:6-7.
15. Plato. In: Grube GM, transl. *Republic*. Indianapolis: Hackett Publishing; 1981:76-7.
16. Beecher HK. The powerful placebo. *JAMA*. 1955;159:1602-6.
17. Murphy DJ, Murray AM, Robinson BE, Campion EW. Outcomes of cardiopulmonary resuscitation in the elderly. *Ann Intern Med*. 1989;111:199-205.
18. Lantos JD, Miles SH, Silverstein MD, Stocking CB. Survival after cardiopulmonary resuscitation in babies of very low birth weight. *N Engl J Med*. 1988;318:91-5.
19. Freeman JA, Chalmers TC, Smith H Jr, Kuebler RR. The importance of beta, the type II error and sample size in the design and interpretation of the randomized control trial. Survey of 71 "negative" trials. *N Engl J Med*. 1978;299:690-4.
20. Bedell SE, DeBianco TL, Cook EF, Epstein FM. Survival after cardiopulmonary resuscitation in the hospital. *N Engl J Med*. 1983;309:569-76.
21. Gordon M, Harowitz E. Cardiopulmonary resuscitation of the elderly. *J Am Geriatr Soc*. 1984;32:930-4.
22. *Life-Sustaining Technologies and the Elderly*. Washington, DC: U.S. Congress, Office of Technology Assessment; 1987: publication OTA-BA-306, 167-201.
23. Johnson AL, Tanser PH, Ulan RA, Wood TE. Results of cardiac resuscitation in 552 patients. *Am J Cardiol*. 1967;20:831-5.
24. Taffet GE, Tensdale TA, Lucht RJ. In-hospital cardiopulmonary resuscitation. *JAMA*. 1988;260:2069-72.
25. Knass WA, Draper EA, Wagner DP, Zimmerman JD. APACHE II: a severity of disease classification system. *Crit Care Med*. 1985;13:818-29.
26. Knass WA, Draper EA, Wagner DP, Zimmerman JE. An evaluation of outcome from intensive care in major medical centers. *Ann Intern Med*. 1986;104:410-8.
27. Imbus SH, Zawacki BE. Autonomy for burned patients when survival is unprecedented. *N Engl J Med*. 1977;297:308-11.
28. Pflum F, Posner JB. *The Diagnosis of Stupor and Coma*. 3d ed. Philadelphia: F.A. Davis; 1960.
29. Cranford RE. The persistent vegetative state: the medical reality (getting the facts straight). *Hastings Cent Rep*. 1968;18:27-32.
30. Katz J. *The Silent World of Doctor and Patient*. New York: Free Press; 1984.
31. Emery DD, Schaeferman LJ. Cost-effectiveness analysis in health care. *Hastings Cent Rep*. 1989;19:8-13.
32. Yarborough M. Continued treatment of the fatally ill for the benefit of others. *J Am Geriatr Soc*. 1988;36:63-7.
33. Perlman HS. Ethics at the end of life: practical principles for making resuscitation decisions. *J Gen Intern Med*. 1986;1:170-6.
34. Miles SH. Futile feeding at the end of life: family virtues and treatment decisions. *Theor Med*. 1987;3:293-302.
35. Jecker NS. Anencephalic infants and special relationships. *Theor Med*. 1990 [In press].
36. Jecker NS. The moral status of patients who are not strict persons. *J Clin Med*. 1990 [In press].
37. Schaeferman LJ, Spragg RG. Ethical decisions in discontinuing mechanical ventilation. *N Engl J Med*. 1988;318:984-8.
38. Daniels N. Why saying no to patients in the United States is so hard: cost containment justice, and provider autonomy. *N Engl J Med*. 1986;314:1380-3.



Sherry Thurston, Sneads Ferry, NC. *Feeding the Flock* (detail), 1998. Photograph. 8" x10".

## Ethical Issues in End-of-Life Care

*Robert M. Walker, MD*

*The issues associated with appropriate end-of-life interventions involve ethical, moral, and legal decisions by patients and their physicians.*

**Background:** *Physicians who treat patients approaching the end of life often face moral, ethical, and legal issues involving shared decision making, futility, the right to refuse medical treatment, euthanasia, and physician-assisted suicide.*

**Methods:** *The author examines cases that involve these issues and also reviews the ethical principles that guide current medical practice. Issues such as end-of-life ethical questions, the right to life-sustaining therapy, medical futility, the distinction between killing and allowing to die, and physician-assisted suicide are discussed.*

**Results:** *The principal problem involves the appropriate use of technology at the end of life. While developments in technology have enhanced our ability to prolong life, issues have also arisen regarding the resulting quality of life, the sometimes marginal benefits to our patients, and the burdens that this technology imposes on patients, families, and society.*

**Conclusions:** *Legal and ethical issues continue to confront patients, courts, and physicians. A better understanding of these issues and an awareness of the availability of effective palliative care will help physicians, patients, and families adequately address the end-of-life issues that are an intrinsic part of medical care.*

### Introduction

Medicine's technical advances of the past few decades have cast a shadow over its long-held ethic of compassionate care. The main problem has been the appropriate use of technology at the end of life. Should it be used on everyone, regardless of the chance of successful outcome or the burdens it imposes? If not, what ethical parameters guide the use and non-use of medical interventions?

These questions are most sharp at the end of life because the burdens of intervention are often high, the benefits are marginal, and quality of life is markedly diminished. This article reviews the ethical principles that guide medical practice and then focuses on end-of-life ethical issues such as the right to life-sustaining therapy, medical futility, the distinction between killing and allowing to die, and physician-assisted suicide.

### Ethical Principles

The core principles of medical ethics date from antiquity and are commonly labeled "beneficence" and "nonmaleficence." The principle of beneficence holds that physicians should aim to "benefit the sick," while nonmaleficence means to "do no harm" in the process. These principles are reflected in medicine's chief goal, which is to help the sick by returning them to health and lessening the suffering and decline that is often associated with their diseases.<sup>1</sup> The central question in the care of the dying is the appropriate use of life-sustaining interventions. In some cases, there is little or no benefit to be gained by these interventions, and yet the potential for significant harm commonly remains. Ordinarily, when the benefits are clearly outweighed by the potential harms of intervention, the use of that intervention is properly regarded as inappropriate. But who has the ultimate authority to decide the matter of appropriateness? Should it be the physician alone? Should inappropriateness be decided at the policy level?

From an ethics point of view, the patient is the one to decide about forgoing life-sustaining interventions, based on the third ethical principle — patient autonomy. The principle of autonomy, or respect for persons, has its roots in analytic philosophy and has become synonymous with the concept of self-determination.<sup>2</sup> This concept was expressed well by Justice Cardozo in a famous medical malpractice case: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."<sup>3</sup>

The principle of autonomy lies at the root of the medical and legal doctrine of informed consent and also at the root of decisions by patients to forgo life-sustaining treatment at the end of life.

The fourth ethical principle is that of distributive justice, which guides the fair allocation of medical resources. Justice considerations arise in end-of-life care when one compares the high cost of marginally beneficial end-of-life care to the lack of funding for the basic care of a large portion of our country's residents. While the issues surrounding medical costs and the design of just health care systems are complex and important, they require a social policy level approach and should not be left simply to the physician at the bedside. The principle of justice is mentioned to set it apart from end-of-life ethics decisions at the bedside. In the current climate of increasing desire for a dignified death, if a better job were done of honoring patients' wishes to forgo expensive life-prolonging intervention, then both justice and autonomy would be served.<sup>4</sup>

### Shared Decision Making

In most cases, ethical treatment decisions should be shared between physician and patient. The physician has an obligation to inform the patient of established treatment options and then to recommend the treatment he or she believes is in the patient's best medical interest.<sup>5</sup> The patient then accepts the physician's recommendation and consents to treatment, chooses an option other than the recommended one, or chooses to forgo the treatments altogether. In each case, the physician fulfils the ethical obligation to benefit the patient while minimizing harm. The patient, in turn, exercises his or her autonomy in either choosing treatment or refusing it. Even though this shared decisional process may result in conflict, in most cases of treatment refusal the patient's autonomy should prevail. This does not mean that the physician should not attempt to persuade the patient to act in what the physician believes to be the patient's best medical interest, but it does mean that the physician should not attempt to coerce the patient's decision.

### The Right to Refuse Medical Treatment

The right to refuse medical treatment is well established in medicine and in law. The legal tradition of the right to be left alone has deep roots. When cases arose asserting that a patient has a right to be free of unwanted medical intervention, the right was readily recognized and clearly affirmed.<sup>6,7</sup> These legal cases can be categorized into four classifications: (1) the patient with decision-making capacity, (2) the patient without capacity but who had earlier expressed treatment preferences for end-of-life care either verbally or in a written advance directive document, (3) the patient without capacity who had made no prior expression of treatment preferences, and (4) the patient who never had the capacity to make treatment decisions. In cases of patients with intact decision-making capacity, courts have ruled that such patients have the right to refuse medical interventions even when those interventions are life-sustaining. In *Satz v Perlmutter*,<sup>8</sup> a competent ventilator-dependent patient with amyotrophic lateral sclerosis wanted his ventilator discontinued and was allowed by the court to direct physicians to remove the ventilator.

In cases where patients have lost their capacity but had indicated in an advance directive that they did not want life-prolonging procedures, courts have ruled that their advance wishes should be followed. In situations where there is no written advance directive and the patient lacks decision-making capacity, courts have articulated standards for proxy decision making. This means that an individual other than the patient assists in decision making for the patient. The courts have reasoned that the loss of capacity to exercise the right to refuse treatment does not entail the loss of the right itself. They have further reasoned that in order to prevent the right from being extinguished in a practical sense, another person must exercise the right on the patient's behalf.

In cases where patients have expressed their wishes prior to losing capacity, the proxy decision makers should follow those wishes rather than make their own judgment about what to do. This is referred to as "substituted judgment" because the proxies substitute the patients' prior judgment about treatment matters for their own. This is not only an important legal concept, but also one that has practical application in counseling proxy decision makers at the bedside. Many proxies feel uncomfortable in deciding to forgo life-prolonging interventions because they see themselves as deciding between life or death for another person. The actual role of the proxy, however, is not to make the decision but to help carry out the patients' wishes. This is relatively easy when the patient has taken the time to complete an advance directive. In such cases, the proxy's role is often to clarify the interpretation of vague statements in the directive and to help craft the details of the patient's palliative care plan. Matters can become more difficult when the proxy must recall past oral statements by the patient about how he or she would want to be cared for in an end-of-life or terminal situation.

In cases where the patient has never communicated thoughts about end-of-life care or has never had the capacity for such thoughts, the proxy cannot make a substituted judgment since no prior judgment by the patient exists. Despite this, one early court case strained to apply the substituted judgment standard in deciding whether to authorize chemotherapy to treat leukemia in a 67-year-old never-competent man with an approximate mental age of 2.<sup>9</sup> Most courts, seeing the illogic of basing decisions on the imagined choices of the never-competent, have rejected this approach as misguided. They have instead adopted the "best interest" standard of proxy decision making. This standard simply requires the proxy to make the decision that is in the patient's best medical interest. It is not the proxy's decision alone; it is a process of shared decision making with the attending physician.

A patient's right to refuse treatment, whether exercised directly or by proxy, is not an absolute right. Many state courts have identified four social interests that must be balanced against a person's right to be free of unwanted medical intervention. These are the preservation of life, the prevention of suicide, the protection of third parties, and the preservation of the ethical integrity of the medical profession. In most treatment refusal cases, these state interests are not found to outweigh a competent adult's right to refuse unwanted

medical intervention. However, in some cases, the right to refuse treatment is overridden. An example of this is a court-ordered blood transfusion to save the life of a single-parent Jehovah's Witness who would leave minor children as wards of the state if life-saving transfusion is withheld. In cases such as this, many courts have held that the state's interest in protecting the children outweighs the parent's right to refuse unwanted transfusion, even though the reason for refusing is based on a deeply held religious belief.

### Forgoing Treatment on the Basis of Medical Futility

It is well established that there is no ethical obligation for physicians to provide treatment that is futile.<sup>10,11</sup> The question, however, is what constitutes futile treatment. Unfortunately, medical futility can have several meanings. Failure to clarify the term can lead to miscommunication and masking of differing value judgments and biases, thus enabling a subtle form of paternalism.<sup>12</sup> For example, in explaining to a patient that cardiopulmonary resuscitation (CPR) would be futile, it is not uncommon for the physician to mean that CPR would have a very low chance of success, while the patient interprets the meaning of term to be that treatment has no possibility of success. If the patient then agrees to forgo CPR, the decision will have been based on a misunderstanding. For this reason, it is important to be explicit about these matters by using plain language instead of hiding value judgments under the cloak of medical futility.

Medical futility concepts can be organized as follows: The first division of futility is divided into the categories of post-hoc futility and predictive futility. In post-hoc futility, treatment has been tried and has failed. We see in retrospect that a treatment that perhaps held out some hope has proven to be futile. Post-hoc futility is useless for those who want to use futility as a reason not to try a treatment in the first place. Predictive futility, on the other hand, involves predicting that a treatment will be futile and therefore should not be tried.

Predictive futility can be divided into several types: conceptual futility, probabilistic futility, physiologic futility, and doctor-patient goal disagreements. Conceptual futility is futility based on a particular concept or definition, the example being brain death. The medicolegal concept of death holds that ventilator-dependent patients who have suffered "irreversible cessation of all functions of the entire brain including the brain stem" are dead.<sup>13</sup> In such cases, the ventilator is by definition a futile intervention because it cannot bring the patient back to life. While "brain death" has become a medicolegal standard in the United States, some have voiced religious objections to the standard. Because of this, at least two states have passed laws allowing a "religious exemption" to the brain-death standard. Apart from religious reasons, cases have occurred where family members simply do not accept that their "brain-dead" loved one is in fact dead. In these cases, the law would allow physicians to discontinue the ventilator without family permission. In practice, however, despite the fact that continued ventilator use is conceptually futile, time is usually given to the family to come to terms with the patient's death before the ventilator is removed.

Probabilistic futility means that a treatment with a very low chance of success can properly be regarded as futile. For example, some would call a 1% chance of surviving CPR as futile CPR. This kind of futility is never absolute, and it entails making value judgments about what risks are worth taking. Because of this, physicians should not make unilateral futility judgments because their values may not reflect those of the patient. Instead, the information should be communicated to the patient, and a process of shared decision making should be followed.

Physiologic futility comes in two forms. The first is called medical nonsense; the second is medical impasse. An example of medical nonsense is a patient's request for antibiotics to treat a viral upper-respiratory infection. In this case, the physician can unilaterally refuse to give antibiotics on the ground that antibiotics are a futile intervention. There is no possibility of benefit, while potential for harm remains. Medical impasse occurs when a person's illness makes it physiologically impossible for sensible treatments to work. An example of this is a person with AIDS and pneumocystis pneumonia who develops adult respiratory distress syndrome. If such a person were to suffer cardiac arrest, ordinarily CPR would be a sensible and indicated response. However, in the case where the infection has proven refractory to all available treatments and where gas exchange has become critically impaired and is worsening, CPR cannot possibly be effective. Once acidemia and ischemia produce cardiac arrest, it is physiologically impossible for CPR and cardiac medication to restore vital air exchange. Thus, there is medical impasse and absolute physiologic futility. In such a case, a physician can unilaterally decide not to perform CPR on the ground of medical futility.

The last futility concept is doctor-patient goal disagreement. In the case of Helga Wanglie,<sup>14,15</sup> a ventilator-dependent patient in a permanent vegetative state, the physician regarded the ventilator as futile because it could not improve and thus benefit the patient. The patient's husband, however, did not see the ventilator as futile because it was keeping his wife alive. In this case, we have a disagreement between two different goals. The ventilator could not meet the physician's goal of health improvement, but it could meet the husband's goal of life prolongation. In such cases where value differences exist about what goals are worth pursuing, the decision should be a shared one between the doctor and the patient (or the patient's proxy). The physician would not be justified in making a unilateral decision to discontinue the ventilator. On the other hand, the physician who believes that continued ventilation would be morally objectionable is free to preserve his or her moral integrity by withdrawing from the case.

### Killing vs Allowing to Die

When life-sustaining treatment is discontinued, whether on the ground of medical futility or patient autonomy, there can be uneasiness about our actions. This often stems from failing to distinguish clearly between causing the patient's death or merely allowing the patient to die. In the typical scenario of a permanently unconscious ventilator patient, the patient is alive until the physician removes the

ventilator, whereupon the patient soon dies. The proximity of the patient's death to the physician's removal of the ventilator leads some physicians to wonder whether they have indeed caused the patient's death. By contrast, in the case where the ventilator is never utilized, death is neither caused nor precipitated by the physician but is instead the result of the patient's disease process. Because of this, many physicians are more comfortable with not starting treatment than with stopping it.

The counter to this concern is to regard the ventilator as an optional form of external support. While the ventilator does sustain life, it is clear that a person who wishes to forgo it has the right to do so. An unambiguous example is that of an irreversibly incapacitated, terminally ill patient who had earlier prepared an advance directive stipulating that mechanical ventilation should not be used if his or her capacity was irreversibly lost and if the disease was terminal. If these criteria are met before the need for ventilation arises, then the ventilator should not be started. On the other hand, if the ventilator was started before the patient became terminal and irreversibly incapacitated, the ventilator should be discontinued once these conditions have been clearly met. In discontinuing the use of the ventilator, the physician is not causing death but is appropriately removing a form of external medical support that the patient refused in advance. The natural forces of the patient's illness continue unopposed once the ventilator is removed, and quite predictably, the patient dies. The patient's death is caused by the disease rather than by the physician.

### Euthanasia and Physician-Assisted Suicide

In the case of euthanasia, the physician takes the patient's life. While the term euthanasia has been variously defined, in this article euthanasia refers to an act in which a physician directly and intentionally causes a patient's death by medical means. For example, a physician commits euthanasia when he or she deliberately injects a lethal amount of potassium chloride into a patient for the express purpose of terminating that patient's life. Thus described, euthanasia is commonly distinguished from murder because its motive is merciful rather than malicious; however, it is nevertheless a form of homicide and remains illegal in the United States. When the physician performs euthanasia with the consent of the patient, it is called voluntary euthanasia. When euthanasia is performed without patient choice, such as may be the case with incapacitated patients, it is called nonvoluntary or nonchoice euthanasia. Involuntary euthanasia involves performing euthanasia against the patient's wishes.

Physician-assisted suicide is a form of voluntary euthanasia that is legal in the state of Oregon.<sup>16</sup> In Oregon, a physician can prescribe a lethal amount of medication for a patient so that the patient can commit suicide with the medication if he or she so chooses. It is a form of voluntary euthanasia because the physician agrees to participate in a plan to cause the patient's death and supplies the lethal medication that is used to cause death. In voluntary euthanasia, as defined above, the physician acts alone to terminate the patient's life, whereas in physician-assisted suicide, the physician and the patient act together to cause the patient's death.

The Hippocratic Oath, to which American medicine has traditionally appealed for its moral bearings, expressly prohibits physician-assisted suicide and euthanasia. The oath reads, "Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course."<sup>17</sup> It is telling to note that during the time of Hippocrates, when medicine's power to effectively treat disease and ameliorate suffering was far less than it is today, assisted suicide and euthanasia were regarded as radically incompatible with physicianhood. This at least suggests that those in favor of physician-assisted suicide and euthanasia have very different ideas about physicianhood and the moral limits of medicine. It is also telling that the public interest in physician-assisted suicide comes at a time when the palliative powers of American medicine are greater than they have ever been before. This suggests that perhaps the public is significantly unaware of the advances and availability of palliative medicine or that palliative care it is woefully underutilized. While this is no doubt the case for some portion of the public, others in our society wish to have physician-assisted suicide and euthanasia as options along with the benefits of palliative care. The chief argument for this is based on autonomy, but it is an argument that begs the question of whether it is proper for a physician to play an active role in causing a person's death via lethal doses of medication.

In euthanasia and physician-assisted suicide, the core ethical issue for medicine is the rightfulness or wrongfulness of a physician intending and acting to cause the death of a patient. Unfortunately, this issue is easily obfuscated. An example of this occurred in *Quill v Vacco*, one of two recent federal appellate court cases that argued for a right to hasten death.<sup>18,19</sup> The Quill opinion argued that a person has a right to hasten death but that laws prohibiting physician-assisted suicide prevent the equal exercise of this right. This can be illustrated with an example involving two similarly situated patients. Patient A has terminal lung disease and is on a ventilator, while patient B is terminal with AIDS and is not on a ventilator. According to the Quill court's logic, patient A is able to hasten their death by directing that the ventilator be discontinued, while patient B cannot hasten their death because the law regards physician-assisted suicide as a crime. The court concludes that laws prohibiting physician-assisted suicide were unconstitutional because the laws set up an inequality in the law.

The reality is that there never has been a right to hasten one's death, but a right to refuse unwanted medical intervention has been recognized. Patient A exercises the right to refuse unwanted intervention by directing doctors to discontinue the ventilator. Similarly, patient B exercises the right to refuse unwanted intervention by deciding not to go on a ventilator in the first place. The Quill court's view that patient A is hastening death by discontinuing the ventilator shows that they do not understand the difference between killing and allowing to die. Furthermore, in suggesting that discontinuing the ventilator hastens death, the court implies that patient A's ventilator has somehow become intrinsic to patient A. The reality is that the ventilator is a form of optional external medical support. The decision to discontinue its use is not a decision to hasten death but a decision to cease forestalling it. Failure to make careful distinctions about

killing and allowing to die and about hastening and forestalling death add to the confusion surrounding the physician's role in end-of-life care.

### The Legal Slippery Slope

The US Supreme Court rejected the arguments of the two federal appellate courts that laws prohibiting physician-assisted suicide were unconstitutional.<sup>20,21</sup> However, the Supreme Court did not say that states were obligated to prohibit the practice. This leaves the door open for states to follow Oregon in legalizing physician-assisted suicide. The Oregon law was careful not to characterize physician-assisted suicide as a right, but if it is ever deemed to be one in future court decisions, this designation will almost certainly entail the extension of this right to incompetent patients, just as has been the case with the right to refuse treatment. With the latter, court after court has agreed that losing the capacity to exercise a right does not mean that the right no longer exists. Furthermore, to prevent the right from being extinguished in a practical sense, some other person must exercise the rights of the incapacitated patient for that patient. Thus the process of proxy decision making came into being. This same process could take place with physician-assisted suicide, especially when the courts begin to see cases involving incapacitated patients who had earlier stipulated that they would want physician-assisted death in the event of terminal illness and irreversible loss of capacity.

If physician-assisted suicide is regarded as a right, it will very likely be extended to incapacitated patients in order to avoid the practical extinguishing of their rights. However, since the patient will not be able to exercise it, proxy decision making would be utilized. Also, since the incapacitated patient cannot participate in physician-assisted suicide, it will become the physician's act alone. Thus we will have moved to euthanasia. Still further, if this right is extended to the case of the incapacitated terminal patient who left no past wishes, as it has been in the case with the right to refuse treatment, then we will have legalized nonvoluntary euthanasia. Proxies and physicians will then be making euthanasia decisions because it is deemed in the patient's "best interest" to be dead. The fact that such potential exists in our legal system, which judges cases and advances law by ruling on precedent, should give us pause. Alternatively, the current effectiveness of palliative care in addressing the full spectrum of end-of-life issues leaves us with no good reason to throw open the door of euthanasia that Oregon has left ajar. Efforts should instead be put toward optimizing the use of palliative care and making it available to all who need it.

### References

1. Kass LR. *Is there a medical ethic? The hippocratic oath and the sources of ethical medicine. Toward a More Natural Science: Biology and Human Affairs.* New York, NY: Free Press; 1985.
2. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 4th ed. New York, NY: Oxford University Press; 1994.
3. *Schioendoff v The Society of New York Hospital* (1914).
4. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine.* 4th ed. New York, NY: McGraw-Hill, Health Professions Division; 1998.
5. Ingelfinger FJ. Arrogance. *N Engl J Med.* 1980;303:1607-1611.
6. Emanuel EJ. A review of the ethical and legal aspects of terminating medical care. *Am J Med.* 1988;84:291-301.
7. Gostin LO. Deciding life and death in the courtroom. From Quinlan to Cruzan, Glucksberg, and Vacco: a brief history and analysis of constitutional protection of the "right to die." *JAMA.* 1997;278:1523-1528.
8. *Satz v Permuter*, 379 So 2d 359 (1980).
9. *Superintendent of Belchertown v Saikewicz*, 370 NE2d 417 (Mass1977).
10. Hippocrates: the art. In: Reiser SJ, Dyck AJ, Curran WJ, eds. *Ethics in Medicine: Historical Perspectives and Contemporary Concerns.* Cambridge, Mass: MIT Press; 1977:6-7.
11. American Medical Association, Council on Ethical and Judicial Affairs. *Code of Medical Ethics: Current Opinions with Annotations.* Chicago, Ill: The Association; 1996:8.
12. Lantos JD, Singer PA, Walker RM, et al. The illusion of futility in clinical practice. *Am J Med.* 1989;87:81-84.
13. *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Defining Death: A Report on the Medical, Legal, and Ethical Issues in the Determination of Death.* Washington, DC: Government Printing Office; 1981.
14. Miles SH. Informed demand for "non-beneficial" medical treatment. *N Engl J Med.* 1991;325:512-515.
15. Angell M. The case of Helga Wanglie: a new kind of "right to die" case. *N Engl J Med.* 1991;325:511-512.
16. Oregon Death with Dignity Act, Or. Laws ch. 3 (initiative measure no. 16), 1995.
17. Hippocrates, trans. Jones WHS. *The Loeb Classical Library.* Cambridge, Mass: Harvard University Press; 1923.

18. *Quill v Vacco*, 80 F3d 718 (2d Cir 1996).

19. *Compassion in Dying v Washington*, 850 F Supp 1454 (DC Wash 1994).

20. *Washington v Glucksberg*, 117 s Ct. 2258 (1997).

21. *Vacco v Quill*, 117 s Ct 2293 (1997).

*From the Division of Medical Ethics and Humanities, Department of Internal Medicine, University of South Florida College of Medicine, Tampa, Fla.*

*Address reprint requests to Robert M. Walker, MD, at the Department of Internal Medicine, Division of Medical Ethics and Humanities, MDC Box 19, University of South Florida College of Medicine, 12901 Bruce B. Downs Boulevard, Tampa, Fla 33612-4799.*

*No significant relationship exists between the author and the companies whose products may be referenced in this article.*

 [Back to Cancer Control Journal Volume 6 Number 2](#)