

Medical Futility – an Ethical Issue for Clinicians and Patients

by James J. Walker

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The scene is not that unusual. A ninety-three-year-old patient has been moved from a skilled nursing facility to an Intensive Care Unit at a local medical center because she is now in multiorgan failure.



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The distraught family is at the bedside, demanding

that “everything be done” to save their mother’s life. The caregivers are convinced that “everything” cannot be done, so they decide that some potential medical interventions are “medically futile,” and will not be offered if and when the patient requires treatment.

Medical futility is a relatively recent category that healthcare providers use to decide when to forgo or withdraw medical treatment. The phrase has its roots in two developments that affect how medicine is practiced in the United States: the rapid development of modern medical tech-

nology and cultural and legal movements in the late 1950s and 1960s.

Modern medical technology has been growing exponentially since World War II and the Korean Conflict, and physicians have not always thought about when or how certain medical interventions may actually benefit their patients.

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The second development is a cultural and legal one. It has to do with the development of what is now called “patient autonomy,” which arose in the 1950s as a reaction against the standard model of medical decision making, namely, “physician paternalism.”

The civil rights movement certainly contributed to patients claiming their rights over their own bodies and medical decisions. Some claim that the category “medical futility” actually arose as physicians attempted to reclaim authority over the medical decision-making process from their emancipated patients.

If a technology can be declared “medically futile” by a physician, then the patient and family will not be told about that technology, and the physician will not provide it, even if the family asks for or demands it.

No doubt other factors have also led to the development and application of the category of futility, including some basic assumptions about life, death, and the delivery of healthcare that are part of the American

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From the Contributing Editor

When Enough Is Enough — The Predicament over Futility

Since January, a task force of Center staff and members of the Kansas City Area Ethics Committee Consortium have labored diligently to craft a guidelines document on the subject of medical futility. Our discussions and the resulting document would, we felt certain, give area healthcare providers and institutions new ways to avoid and manage intractable disagreements over the use of treatments believed to be futile, that is, medically ineffective or nonbeneficial. That hope continues, and we will soon begin a second phase of the project. We plan to gather feedback from various community groups before sharing our recommendations with healthcare institutions regionally and nationally.



Michael Brannigan

Yet, as neatly packaged as this coordinated effort may appear, the reality is somewhat messier. To begin, in the absence of consensus, “futility” is a cryptic, even misleading notion. Second, trust in clinical providers has eroded in practice and ideas about the nature and scope of authority have become less clear; and these trends may continue in a health system increasingly fragmented by such factors as intensified specialization, ongoing fear of litigation, institutional pressures to contain costs, and systemic dysfunctions. Health professionals in the trenches and patient decision makers, their

surrogates, and family members know well how easy it is to use patient autonomy or medical expertise to trump the other’s authority. In such cases, matters of futility can erupt into full-blown moral conflicts in which we need to critically examine and weigh patients’ rights, limits to these rights, professional conscience and integrity, “best practices” in healthcare, unjustified unilateral treatment decisions by physicians, institutional constraints, and the ever-present reality of dwindling medical resources. Clearly, the issue of futility is enormously complex, and the above concerns cannot be sufficiently addressed within the scope of this publication.

In the face of this complexity, however, what is certain is that we must eschew the potential dangers of exploiting “futility” as the less taxing “fix” and recognize the need for open and honest communication among all stakeholders.

As a society, we need to take a hard look at our perception and expectations of modern medicine and, ultimately, at what ought to be the proper goals of medicine and healthcare. And, throughout the process, we need to reassure patients and their families that they will continue to receive comfort and care.

Articles in this issue of *Practical Bioethics* capture the predicament over futility in specific ways. Bear in mind, however, that the authors’ views and positions are neither comprehensive nor intended to be. As we noted above, futility’s terrain is relentlessly complex.

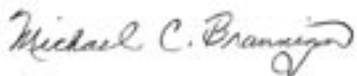
Edmund Pellegrino offers a valuable depiction of this terrain as a tricky relationship between a treatment's effectiveness and its benefits and burdens. He also shares how his theological views impact his thinking. His transparent and measured approach is indispensable, and while some of his points may be arguable, his warning about potential abuses of futility makes good sense.

Others may find room to challenge James Walter's bedrock typology and vital distinction between effect and benefit. Nonetheless, the distinction is helpful, particularly when it is set in view of the wider, critical contrast between clinical and personal goals. His article is another rich contribution to the discussion.

We thank both authors for shedding light on an overheated topic, for sharing their maps to help guide us through the terrain of futility. At the same time we need to be careful not to rely on just one map. Moreover, unless we tackle what I consider to be the core underlying issue of trust, guidelines will be of limited usefulness.

Guidelines are no substitute for genuine humane connection, though they should point us in that direction. Without insisting on work to restore sufficient trust between healthcare organizations and the communities they serve, institutional documents will always be near-sighted.

In the spirit of trust, we welcome you to this issue, and we invite you to join us in a collective step toward dialogue and hopeful resolution.

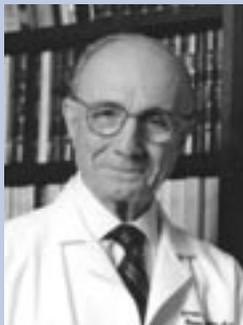


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Decisions at the End of Life — The Abuse of the Concept of Futility

by Edmund D. Pellegrino

Common sense and long clinical experience recognize that there comes a point in the care of any patient when the capabilities of medicine to cure, ameliorate, or reverse a disease process have been exhausted. At that point, further medical intervention is no longer in the interest of the patient to continue. Indeed, continuance of treatment under those circumstances may impose further suffering



Edmund Pellegrino

and other burdens on the patient — physical, emotional, and fiscal.

Recognition of this fact has generated a traditional principle that there is no moral obligation to provide a futile treatment.

This principle turns on the definition of futility. This is a much debated question today for several reasons.

The expansion of medical capabilities to sustain life and prolong dying has resulted in unprecedented ways that many patients may be kept alive for indefinite periods whereas previously they would have died. As a result, the majority of patients in modern hospitals today die as a result of a deliberate decision to withhold or withdraw treatment. These decisions have been complicated by relatively new clinical dilemmas like persistent vegetative states, do not resuscitate orders, living wills, durable powers of attorney, the expansion of patient and

surrogate autonomy and participation in clinical decisions of all kinds, even the continuance of nutrition and hydration. If these decisions are not to be simply matters of opinion or choice, some criterion must be used to guide when it is morally valid to withdraw or withhold treatment.

For most of the history of medicine, “futility” was based on the physician's opinion of diagnosis, prognosis, and future course of the disease as well as the relationship between benefits and burdens associated with continued treatment. Until 1914, when the legal right of a patient to refuse life-saving treatment was asserted, physicians made the decision of futility. Since then, and increasingly in recent years, the right of refusal has been extended to families and surro-

“The majority of patients in modern hospitals today die as a result of a deliberate decision to withhold or withdraw treatment.”

gates. Many patients and families today interpret the negative right of refusal as a positive right to demand treatment even over the clinician's judgment to the contrary.

With these profound changes in medicine's capabilities and the rights of patients and families to participate in decisions, the concept of futility as traditionally conceived has come under

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Decisions at the End of Life

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extensive criticism. Some have asked “whose futility” pointing to the need for patient or family opinion about the value of treatment. Others have called futility an empty, indefinable, or useless concept. Still others have said that only the patient or the family can say what is “futile.” At the other extreme are those who insist futility can only be determined by the physician. Others believe it can be quantified in some way. Others still would define futility in terms of utility or economics. Others increasingly would make it a matter for hospital policy or committee decision.

Those who call for the abandonment of the concept have no substitute to offer. They persist in making decisions with, more or less, covert definitions. The common sense notion that a time does come for all of us when death or disability exceeds our medical powers cannot be denied. This means that some operative way of making a decision when “enough is enough” is necessary. It is a mark of our mortality that we shall die. For each of us some determination of futility by any other name will become a reality.

Some working definition therefore must be recognized by which the criterion of futility can be judged. Such a definition begins with the ordinary dictionary usage of futility as an ineffectiveness to attain a stated goal. In clinical medicine that goal may be cure, relief of pain and suffering, amelioration of disability, reversal of the natural history of the disease, or some other objective in some way meaningful to the patient.

Given today’s confluence of medical capabilities and patient and family autonomy, futility judgments however defined must include the values of physician, patient, family, and

“Futility judgments however defined must include the values of physician, patient, family and other team members.”

other team members. Many of the objections to the traditional decision on clinical futility can be accommodated if the definition includes both the clinical and the patient and family considerations.

Such a definition would include weighing three factors — effectiveness, benefits, and burdens. Effectiveness is determined by the clinician’s objective assessment of whether, and to what degree, any intervention would alter the natural history of the disease or a symptom. This is the clinical component. It is based on clinical knowledge and experience of diagnosis, prognosis, and therapeutic options. In this assessment, age, quality of life, and eco-

nomics would be ancillary but not per se determinative.

Benefit, on the other hand, is patient or family determined. It includes a good or value perceived by them as worthwhile in the life of the patient. Benefit is subjective for the most part. It may include patient or family evaluation of age, quality of life, and economics.

Burdens include physical, fiscal, and emotional consequences of proposed treatments. Burdens are both objective and subjective. They are defined by patients or their surrogates in conference with the physician.

These three components — effectiveness, benefit, and burdens are in fact usually part of futility decisions even if not explicitly stated as such. No mathematical formula is available to give quantitative weight to each. Instead, the proportionality between and among these three components is weighted as we weigh so many other decisions in ordinary life, in a qualitative manner.

This determination requires incremental and serial assessment of all aspects of the patient’s prognosis and clinical condition so that surrogates can prepare to participate meaningfully in setting the goals of therapy. Together all concerned can frame the decision in terms that include the clinical facts as well as the patient’s values.

All of this means physicians must know the patient as well as today’s circumstances of medical care allow. Physicians must also make known to family and the health-care team what they will, or will not do according to their norms of professional and moral integrity. Families and patients will then



Futility decisions will include clinical facts and the patient’s values.

have an opportunity to transfer care to another physician if they deem it necessary. Setting time limits on any decision with frequent reexamination of its validity saves time and makes for less conflict.

Ethics committees can be helpful in facilitating discussion and laying out ethical issues. They can assist in the correlation of clinical facts and values in decisions about futility. But they do not relieve the patient, family, or physician of moral accountability.

There are real dangers of abuse in any concept of futility, overt or covert. Care is never futile. It must be provided throughout the whole life of the patient. Comfort, relief of pain and suffering, and attention to personal needs are all morally mandatory, until the moment of death. Futility cannot be used as justification for assisted suicide, or for voluntary, involuntary or non-voluntary euthanasia. Futility must not be used for justification for withdrawal of all treatments. Each treatment must be evaluated in terms of its end and its futility assessed in relation to that end. Futility is a decision made deliberately and not as a means of accelerating the death of an emotionally draining, difficult-to-manage patient.

It would be a gross abuse to devalue the lives of certain patients — like those in permanent vegetative states; the disabled or handicapped, especially infants; the very old; or those on the margins of society. Nor should futility be defined in terms of the values and kinds of life physicians or other health professionals deem worthy of living. In addition, futility cannot be used as the criterion for taking organs for donation.



Futility involves the weighing of three factors: effectiveness, benefits, and burdens.

A particularly vexing question today is the way some have used the criterion of futility automatically to withdraw nutrition and hydration. This is an abuse of the notion of futility. This is too complex an issue for detailed analysis here. This writer believes that the approach taken by the National Conference of Catholic Bishops (Directive 58) should be the guide. It calls for the presumption that nutrition and hydration will be provided, "...as long as this is of sufficient benefit to outweigh the burdens to the patient." This directive must also take into account the statement of the late pontiff, John Paul II —particularly as it applied to patients in the so-called persistent vegetative state.¹ This group of patients is particularly vulnerable to abuses of any criterion of futility. Their vulnerability underscores the need for a transparent definition.

Clearly to be useful and ethically defensible this approach to defining futility

requires careful deliberation. But there is no substitute for at least an operative definition. It offers a visible, orderly, and systematic cooperative way, taking into account the traditional reliance on clinical evaluation and joining it to participation by the patient and his or her surrogates.

In addition, every attention must be given to the avoidance of conflict. Physicians, patients, families, and health-care team members should engage in futility assessments together. Anticipation of the impending possibility of having to make futility decisions is of the utmost importance as is communication between all participants.

With futility as with other situations where definitions are difficult to come by, or considered too subjective, there is a turn to procedures and policies. Both are now being pursued as substitutes for a definition of futility and as an aid to conflict resolution primarily proposed in a variety of forms.

One procedure, in Toronto, calls for eleven steps²; another, in Houston requires nine steps.³ Two more fix on seven steps: The Texas Advanced Directives Act of 1999,⁴ and the American Medical Association.⁵ All center on communications between decision makers and rely on negotiation, arbitration, mediation, use of ethics committees, or, as in Texas, on statutory devices. All in one way or another must end up answering the question — is the intended treatment futile or not?

These procedural mechanisms simply reduce the definition of futility in individual cases to group definition since some decision must be made about whether a proposed treatment is "appropriate," clini-

Decisions...

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cally indicated, worth doing, or disproportionate — all euphemisms for futility. After all, the purpose of the procedure, no matter how many steps are involved, is a decision to discontinue, withhold, or initiate or continue treatment. Unfortunately, these procedures also move the focus of decision making further from the bedside and give an illusion of greater objectivity.

Futility, by whatever name it is called, or procedure it is arrived by, is an ineradicable fact in the natural history of disease and will remain so as long as humans are mortal.

Notes

1. John Paul II. 2004. Address to the participants in the International Congress on “Life Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas” *National Catholic Bioethics Quarterly* 4(3): 573-576
2. P. Singer, G. Barker, K. Bowman, et al. 2001. “Hospital Policy on appropriate use of Life-Sustaining Treatment” *Critical Care Medicine* 29:187-191
3. Halevy Brody, and B. Brody. 1996. “A Multi-Institutional Collaborative Policy” *Journal of the American Medical Association* 276:571-574.
4. R. Fine. 2000. “Medical Futility and the Texas Advance Directives Act of 1999.” *Baylor University Medical Center Proceedings* 13: 44ff.
5. “American Medical Association. Medical Futility in End-of-Life Care.” 1999. *Journal of the American Medical Association* 281:937-941.

This article was adapted by the author from “*The Dignity of the Dying Person*,” an address to the Fifth Assembly of the Pontifical Academy for Life, 24-27 February 1999).

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Medical Futility – An Ethical Issue...

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ethos. For example, many Americans seem to believe that they can have everything, including healthcare, as long as they can pay for it or have someone else pay for it. Many Americans have an enormous, largely uncritical, faith in modern medicine, and we live in what is often called a “death-denying” culture that relegates death to the boundaries of our social consciousness.

Many people assume that they can make their own decisions, even if they are not informed, and believe that their word on something is or should be the last word. Announcing their will seems to them sufficient reason for others to act or be forced to act on their behalf. These assumptions, which are deep within our culture, lead to many of the conflicts that occur in clinical encounters.

Definitions and Goals

It is important to note at the outset that nothing is said to be “futile” unless it is judged to be so in relation to some type of goal. Thus, nothing is futile in the abstract, but a proposed medical intervention can become futile when it is determined that its goal cannot be achieved, no matter how many times the intervention is repeated.

The English word “futility” comes from the Latin *futilis*, which means “leaky.” As Lawrence Schneiderman and others claim, according to the *Oxford English Dictionary*, “a futile action is leaky, and hence untrustworthy, vain, failing of the desired end through some intrinsic defect.”¹ Like the mythological daughters of Danaus who attempted to draw water with leaky sieves, a futile action is any action that cannot achieve its proper goal no matter how many times

it is repeated. Two types of goals are almost always involved in medical decision making. First, the caregiver will have in mind a *clinical goal* that he or she will seek to achieve on

“Many Americans have an enormous, largely uncritical, faith in modern medicine...”

behalf the patient. But some clarity is needed here. Physicians may seek to produce a “medical effect” rather than a “medical benefit” for the patient, and these are not always the same thing.

As Jane Mary Trau rightly claims, “The effect of a treatment is its impact on a disease, an organ, a pathological condition, the mind or a body part.”² In other words, to produce a “medical effect” as a clinical goal is to target an organ and attempt to make it or its function better.

The problem is that producing a medical effect is not always a medical benefit for a patient. As Trau argues,

The *benefit* of a treatment is the affect of that treatment on the whole person (i.e., the existential human person as a composite of his or her



Interventions may produce a medical effect for the patient but not a medical benefit.

value system, beliefs, goals, and ability to realize those) — in short, the impact on a patient’s life plan, or that person’s long-term benefit.”³

It is clear then that the principal goal of any proposed medical intervention on the part of the physician ought to be to produce a medical benefit for the patient. As Schneiderman et al. argue, “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.”⁴ Thus, many times benefiting an organ (medical effect) can also be a medical benefit, but not always. At the end of life when organs are beginning to fail, it may not be in the best interest of the patient for the physician to make the kidneys produce urine when the patient is dying of metastatic cancer and has no hope of recovery.

The patient’s *personal goal*, the second type of goal in most clinical encounters, may or may not be the same as the physician’s clinical goal. The patient’s goal may be a quality-of-life judgment about the life he or she will have if the caregiver intervenes with medical technology. Though it happens infrequently for the most part, these goals may conflict, and an ethics consultation may be requested.

“The patient’s personal goal... may or may not be the same as the physician’s clinical goal.”

In this framework, “medical futility” is not a single category. Instead, there are two types of medical futility, and they should not be confused or conflated. First, there is “physiological medical futility,” and it is the sole responsibility of the physician to determine

that a proposed or requested medical intervention is futile.

“...the principal goal of any proposed medical intervention on the part of the physician ought to be to produce a medical benefit for the patient.”

Only the physician who is trained in the medical sciences can determine that the proposed medical intervention physiologically can or cannot achieve a clinical goal or a patient/family goal. Thus, we can define “physiological medical futility” (1) as any proposed action or medical intervention requested by a patient or family that cannot medically achieve a desired goal, or (2) any proposed action or medical intervention that cannot produce a medical *benefit* for the patient, even though such an intervention might produce a medical *effect*.

Examples may help to make the case here. When a mother comes to a pediatrician with her sick child and demands antibiotics to cure a viral infection, the pediatrician should refuse. No matter how many times the sick child takes antibiotics, antibiotics will not cure a viral infection. Antibiotics are for bacterial infections, which can be cured by administering antibiotics. In fact, if the physician prescribes antibiotics knowing that they will do no

clinical good, the pediatrician runs the risk of causing harm: the child could eventually develop antibiotic-resistant strains of bacterial infections.

In the second case, when a medical effect can be achieved but not a medical benefit, medicine has lost its reason for acting on behalf of the patient. If the physician acts, the medical intervention is futile or “leaky.” Medicine’s goal for patients is to produce medical benefits, not medical effects that only aid organs or their functions.

There is another type of medical futility, called “qualitative medical futility.” This type of futility is also assessed in relation to a goal, but in this case one *evaluates* the goal of the medical intervention, whether clinical or personal.

For example, although the insertion of a feeding tube for a patient in a permanent vegetative state would feed and hydrate



Physicians decide whether a proposed intervention can or cannot achieve a clinical or patient/family goal.

the patient and thus sustain biological life, the patient or family might judge that this clinical goal is not worth pursuing. So, this medical intervention is declared futile

“Physicians alone should not make [qualitative] judgments of futility; rather it is the responsibility of the patient or the patient’s surrogate to make such decisions.”

on the basis of a quality-of-life judgment made by the patient or the surrogate, and thus it is called “qualitative medical futility.” Physicians alone should not be the ones who make these judgments of futility; rather it is the responsibility of the patient or the patient’s surrogate to make such decisions.

Physicians ought to help their patients make these decisions by helping their patients/families understand the consequences that will accrue to the patient once the proposed medical intervention has occurred. These judgments always involve an evaluation of the goal, and thus they are at their core a value judgment for which the physician has no special training.

Sorting out the Issues

In my responsibilities as an ICU bioethicist at a major medical center in Los Angeles, I regularly make the following seven recommendations to help physicians sort out the issues involved in cases of medical futility.

First, I encourage them to clarify the *clinical goals* early in the treatment plan, then clearly distinguish the possible medical *benefits* from the medical *effects*.

Second, I encourage them to involve their patients and families and discuss their *personal goals* early in the treatment plan.

Third, I urge them not to identify their judgments of physiological futility with judgments about their patients’ quality of life. Though I believe that quality-of-life judgments are sometimes appropriate in medical decision making, these judgments

are ultimately the responsibility of patients or their proper surrogates.

Fourth, I counsel physicians not to ask the patient or family if they want “everything done.” Rather, I encourage them to tell their patients or their families only which medical interventions may or will *benefit* the patient. They should provide a range of possible options, *excluding* all those that are physiologically medically futile.

Fifth, physicians should always emphasize their commitment to benefit the patient with a potential therapy or to care for the patient by palliation. If they are unsure

“Palliation of the patient is almost never futile and thus almost always a medical benefit for the patient.”

whether or not a medical intervention can truly benefit the patient, I encourage them to do a time-limited trial for twenty-four or forty-eight hours. If no true benefit is achieved, then the medical technology ought to be withdrawn.

Sixth, physicians ought to emphasize their commitment not to abandon their patients. Since many studies have shown that patients, particularly at the end of life, fear not only pain and suffering but abandonment by their caregivers, this recommendation is important.

Finally, I encourage physicians to assure the patient and family that they

will control the pain and suffering experienced by the patient. Palliation of the patient is almost never futile and thus almost always a medical benefit for the patient.

Notes

1. Lawrence J. Schneiderman, Nancy S. Jecker, and Albert R. Jonsen, “Medical Futility: Its Meaning and Ethical Implications,” *Annals of Internal Medicine* 112(15 June 1990): 950.
2. Jane Mary Trau, “Futility, Autonomy, and Informed Consent,” *Health Progress* 75(March 1994): 41.
3. *Ibid.*
4. Schneiderman et al. p. 950.

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Control of a patient’s pain and suffering is never futile.

A Family Divided

A Case Study by Robert L. Potter

Discussion Questions by Rosemary Flanigan

A forty-five-year-old man with a three-year history of cardiovascular disease has entered the hospital with a stroke that has paralyzed his right side and caused him to aspirate food of any consistency. His mental status is clouded and there is disagreement as to whether or not he has decisional capacity. His language capacity is only “yes” and “no,” and his responses are inconsistent. The attending physician is convinced that the patient has lost decisional capacity while two family members are equally convinced that he has decisional capacity. The patient’s wife and two other children are ambivalent about his competency to make decisions.

The prognosis for recovery of safe swallowing and speech approaches zero because of the dense damage to the cerebral cortex visible on brain imaging. Two neurological consultants have verified that recovery is likely to be minimal and that permanent, severe disability will be the outcome.

The patient does not have an advance directive. The patient’s wife says that they never did discuss his preferences about life-sustaining treatment. She is convinced that he would not want to live in this disabled condition, but is uncertain whether to request the placement of a feeding tube. Two of her four adult children are strongly opposed to the tube placement, while the other two insist that not to do so would be to “kill our father.” The patient’s wife is torn between these two positions, but finally requests that the tube be placed.

The attending physician and the rest of the treatment team are opposed to placing the feeding tube. Their argument is that the patient has “minimal consciousness” and will not improve. They define this as a futile situation with no reasonable expectation of recovery. Furthermore, two nurses claim that during previous hospitalizations for episodes of cardiovascular events the patient told them that he would not want to be sustained by artificial means — not by ventilators, renal dialysis, or tube feeding. It is their position that the patient has expressed his preference to not be kept alive in a futile situation.

The family requests an ethics consultation.

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Case studies are a regular feature of **Practical Bioethics**. For more cases, visit www.practicalbioethics.org or ask about our members-only online discussion group. Email your requests to bioethic@practicalbioethics.org.

Questions for Discussion

1. The judgment of futility should be a conclusion of a communications process, not a beginning. How would you propose beginning the communication?
 - Who should be present?
 - What information should be shared?
 - What alternatives are on the table?
 - What is your goal in participating in the discussion?
2. The family is divided over whether or not their husband/father should be placed on a feeding tube. Consider and discuss the following statements:
 - The effectiveness of the feeding tube is a clinical matter.
 - The benefits of the feeding tube for the patient depend on the patient’s wishes and quality of life, which the patient or the patient’s surrogate and family must determine.
 - The burdens the treatment (feeding tube) imposes are a consideration for both parties.
3. Role play the discussion. Express your assumptions and loyalties and listen attentively to the other speakers.
4. Evaluate the role playing experience. Did it affect your view of the case?

If yes, how will you advise the family and the healthcare providers?

If not, what is to be done now?
5. How would this case have been different if the attending physician had been the one asking for a consultation?

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Glossary

Futile treatment: any intervention that, on the basis of current medical knowledge and experience, holds no reasonable promise for contributing to the patient's well-being or of achieving agreed on goals of care.

Physiological futility: interventions that physicians deem unable to achieve an intended medical (i.e., somatic) goal.

Normative, evaluative, or qualitative futility: interventions deemed by the patient or patient's surrogate, and family to be inconsistent with the patient's goals and values.

Palliative care: a range of treatments intended to provide relief of pain and suffering, control symptoms, reduce anxiety, and provide comprehensive support to patients – to relieve or alleviate pain and suffering without attempting to cure.

Recent models of care integrate palliative care with curative and restorative therapy across the continuum of care from the

time of diagnosis, throughout the illness, and culminating in total palliative care when cure-oriented care no longer works.

Goals of care: the hoped for, or anticipated, outcomes of medical treatment.

The first goal of care is usually to prevent illness or trauma; the second, to restore health. As illness progresses, other goals may be added and in time become more appropriate, for example, to relieve suffering, to improve the patient's quality of life, to prolong life, to have a good death.

Surrogate: an agent or agents who act on behalf of a person who lacks capacity to participate in a particular decision.

An appropriate surrogate may be (1) identified by the patient (e.g., in a healthcare treatment directive); (2) appointed by a court (e.g., a guardian); or (3) the adult who is most involved with the patient and most knowledgeable about the patient's personal values and preferences.

Art Credits

Page 5, "Stroke"; page 6, "Void." Drawings by Elizabeth Layton, 1978 (photographs courtesy of Don Lambert).



"Grandma" Layton

Elizabeth "Grandma" Layton (1909-1983), wife and mother, newspaper editor and artist from Wellsville, Kansas, discovered contour drawing at age 68, and used it as an antidote to the

depression and low self-esteem that threatened her life. Her works reflect an honest

and deep love for humanity, sensitivity to the suffering of others, and a life-long quest for justice. "Her art," wrote *Parade* magazine, "bursts forth with strong statements in favor of racial tolerance, peace, understanding and compassion."